

**AN ACTION RESEARCH STUDY OF PALLIATIVE CARE FOR PEOPLE WITH  
A DEMENTIA AND THEIR CARERS**

**STEPHEN D M SMITH**

**DOCTOR OF PHILOSOPHY THESIS**

**QUEEN MARGARET UNIVERSITY**

**2009**

## **Research Abstract**

### **An action research study of palliative care for people with a dementia (PWAD) and their carers**

Key words: dementia, palliative care, carer support, assessment, distress

The objectives of this participatory action research were to: identify the palliative care needs of PWAD and their carers in West Lothian; analyse two dementia care services as they develop practice in the assessment and management of distress for PWAD, and supporting carers; determine implications for practice development and service delivery.

Multiple data collection methods were used including; focus groups, interviews, participant observation, reflective accounts, case studies, documentation review, action learning and notes recorded from meetings with staff.

The first phase was a dementia palliative care needs assessment. Eight PWAD, 25 carers and 63 service providers participated in interviews and focus groups. Overall findings were that a palliative care approach provided a useful and appropriate framework to understand the needs of PWAD. Recognition of and support for family carers should take a high priority when considering a model for dementia palliative care.

More specific needs were identified, these included: the need to develop person centred approaches; enhance the management of pain and distress and enhance individual support for carers.

Two services participated in the action phase; a day centre and a hospital ward. Eleven people with a dementia, 28 carers and 86 service providers participated. Services focused on carer support or assessing pain / distress.

Carer support findings: implementing an assessment tool enhanced staffs understanding of carers needs; carers preferred flexible and individual support interventions; family carers experienced cumulative factors that restricted access to support.

Assessment of distress findings: assessing distress from the behaviour of PWAD was complex. The implementation of the Disability Distress Assessment Tool (DisDAT) identified new evidence that it provided a person centred assessment suitable for PWAD.

It was identified that the theoretical concept of relationship centred care, could provide a way of working, that complemented the adoption of a palliative care approach for PWAD, whilst enhancing carer support and assessment of distress practices.

I would like to acknowledge and thank my supervisors Professor Alan Gilloran, Alison Greggans and Belinda Dewar for their support and challenge throughout the process of undertaking this research.

I would also like to thank my family and work colleagues for their encouragement, patience and practical support.

This research was undertaken with the agreement and collaboration of NHS Lothian and the West Lothian Community Health and Care Partnership. I would also like to thank the Big Lottery Fund for their funding.

## List of Thesis Chapters

<b>1</b>	<b>Introduction</b>			
	1.1		Summary of each chapter	11
	1.2		Research aims	15
	1.3		Researchers background and perspectives	16
	1.4		Brief introduction to research: setting the scene	26
	1.5		Phases of the research (Diagram)	28
	1.6		List of abbreviations and acronyms	30
<b>2</b>	<b>Literature Review</b>			<b>31</b>
	2.1		Development of and current issues in dementia care	33
	2.2		Development of and current issues in palliative care	68
	2.3		Development of and current issues in the palliative care of people who have a dementia	82
<b>3</b>	<b>Research Methodology and Methods</b>			<b>101</b>
	3.1		Introduction to chapter	101
	3.2		Research Aims	101
	3.3		Justification for adopting an action research approach in this study	102
	3.4		Action research: methodological approach and development	106
	3.5		Theories about action research	111
	3.6		Development of theory from action research	115
	3.7		Participatory and democratic nature of action research	117
	3.8		First, second and third person enquiry	119
	3.9		Reflexivity in action research	122
	3.10		Action research cycles	124
	3.11		Development of baseline understanding	126
	3.12		Issues of validity and reliability in action research	128
	3.13		Ethical considerations of action research	132
	3.14		Ethical considerations of research involving PWAD and their family carers	138
	3.15		Description and justification of methods used in this	144

			research	
4	<b>Dementia / Palliative Care Needs Assessment</b>			
	4.1		Introduction to chapter	158
	4.2		Aims of conducting the needs assessment	160
	4.3		Definition of terms used in the needs assessment	162
	4.4		Assumptions related to the conduct of the needs assessment process	163
	4.5		The purpose of a needs assessment	165
	4.6		How is a needs assessment conducted	166
	4.7		Limitations of a needs assessment	167
	4.8		Recruitment of participants	169
	4.9		Data collection methods	173
	4.10		Needs assessment data analysis process	175
	4.11		Participation in needs assessment	178
	4.12		Priorities from the needs assessment	188
5	<b>Developing a baseline understanding of participating services and understanding their beliefs and values</b>			191
	5.1		Introduction to chapter	191
	5.2		Aims of developing a baseline understanding of participating services	191
	5.3		Selection of services to participate in the action phase of the West Lothian Dementia Palliative Care Project	193
	5.4		Justification for selection of services to include in doctoral research	194
	5.5		Methods for collecting baseline data	197
	5.6		Baseline understanding of Meadows Day Centre	197
	5.7		Feedback of baseline information at Meadows Day Centre	200
	5.8		Baseline understanding of Almond Ward	201
	5.9		Feedback of baseline information at Almond Ward	204
	5.10		Reflection on the process of developing a baseline understanding of participating services	205
	5.11		Conclusion: Analysis of findings from Almond Ward and Meadow Day Centre	206

	5.12		Understanding beliefs and values about 1) Supporting family carers of PWAD 2) the assessment and management of pain for PWAD	207
	5.13		Aims of beliefs and values clarification focus groups	208
	5.14		Developing beliefs and values questions for focus groups	209
	5.15		Process of conducting beliefs and values focus groups: participation and facilitation	210
	5.16		Key beliefs and values identified from focus group at Meadow Day Centre	211
	5.17		Implications from beliefs and values findings Meadow Day Centre	212
	5.18		Key beliefs and values identified from focus group at Almond Ward	213
	5.19		Implications from beliefs and values findings Almond Ward	214
	5.20		Common themes arising from beliefs and values focus groups	215
6	<b>Action phase: Assessment and management of distress and pain for PWAD: findings and analysis</b>			216
	6.1		Literature review: The assessment of pain and distress for people who have a dementia	216
	6.2		The complexity of identifying distinct causes of distress and Pain	234
	6.3		The implementation of the Disability Distress Assessment Tool (DisDAT) for PWAD.	242
		6.3.1	The DisDAT, a person centred assessment tool	
		6.3.2	The necessity of understanding the term distress for individual PWAD	
		6.3.3	Working with a broad notion of distress rather than focus on a specific problem such as pain was advantageous	
		6.3.4	DisDAT assessments completed by a group of nurses resulted in confidence in the process and high face validity	
		6.3.5	The DisDAT was a useful and appropriate assessment tool	

			for a continuing care setting	
		6.3.6	Implementing the DisDAT raised expectations amongst staff that the management of distress and pain would be made easier.	
7	<b>Action phase: Supporting family carers of people with a dementia: findings and analysis</b>			258
	7.1		Literature review: Supporting family carers of people who have a dementia (PWAD)	258
	7.2		Supporting family carers of PWAD: Findings and analysis	
		7.2.1	The triggers to practice development in carer assessment	273
		7.2.2	Dementia care training: a trigger for practice development	
		7.2.3	The outcomes of practice development activity assessment	
		7.2.4	The learning experience of practice development activity in carer assessment	
	7.3		Factors that restrict access to support for family carers	282
		7.3.1	The impact of continuous care giving	
		7.3.2	The behaviour and responses of the PWAD impact on carer access to support	
		7.3.3	Preference of individual and flexible carer support options	
	7.4		Factors that result in the needs of carers being hidden to service providers	290
		7.4.1	The social façade of PWAD leads to hidden disability resulting in unidentified and unmet carer need	
		7.4.2	The absence of ongoing, 'live' access to professionals, had a negative impact on carer support	
		7.4.3	Services for PWAD and carers were disconnected resulting in blocks to information sharing and access to services	
	7.5		Meadow Day Centre's influence on local health and	302

			social care dementia services	
8	<b>Research conclusions and discussion</b>			
	8.1		Research aim one: Identify the palliative care needs of people with dementia and their carers in West Lothian.	310
		8.1.1	Implementation of person centred care and symptom management	
		8.1.2	Carer support	
		8.1.3	Respite care- key issues	
	8.2		Research aim 2: The assessment and management of pain and distress for PWAD (Almond Ward)	315
		8.2.1	The complexity of assessing distress	
		8.2.2	The appropriateness of the DisDAT for PWAD	
		8.2.3	The necessity of clarifying what is meant by the term distress	
		8.2.4	The benefits of group rather than individual assessment	
		8.2.5	The benefits of considering distress before focusing on pain	
		8.2.6	Nurses expectations following implementation of the DisDAT	
	8.3		Research aim two: Describe and analyse a dementia care service in West Lothian as they develop their palliative dementia care practice: specifically supporting carers of PWAD (Meadow Day Centre)	320
		8.3.1	The benefits of formal carer assessment and a need for individual flexible carer support interventions	
		8.3.2	Factors that restricted family carers access to support	
		8.3.3	Needs of carers hidden to service providers	
	8.4		Research aim three: Analyse the learning that occurs between dementia care practitioners and a facilitator experienced in palliative care during this action research	325



		8.4.1	Researcher developed new understanding of person centred care and relationship centred care	
		8.4.2	The suitability of adopting a palliative care approach for PWAD	
		8.4.3	Researcher as facilitator: introducing evidence into practice	
		8.4.4	Researcher as facilitator: The importance of practice development approaches and reflective practice	
		8.4.5	Inclusion of PWAD and carers facilitated learning, understanding and action	
	8.5		Research aim four: In relation to the assessment and management of pain and distress for PWAD and supporting carers of PWAD, determine potential future implications for practice development and service delivery.	330
		8.5.1	The collective influence of services working together	
		8.5.2	The positive impact of shared reflection, learning and action	
		8.5.3	Questioning the usefulness of conducting a distinct baseline understanding phase with participating services	
		8.5.4	The importance of time and researcher / participant relationship when developing practice	
9	<b>Recommendations from research</b>			
	9.1		Introduction to chapter	334
	9.2		Palliative care for PWAD	334
	9.3		Assessment and management of distress and pain for PWAD	335
	9.4		Supporting family carers of PWAD	336
	<b>List of References</b>			338
	<b>List of Appendices</b>			355

## List of figures

<b>Figure</b>	<b>Description</b>	<b>Page</b>
Figure 1	Phases of the research	30
Figure 2	SENSES Framework	49
Figure 3	Framework for reflexive processes	133
Figure 4	Data analysis processes	156
Figure 5	Outline dementia palliative care needs assessment	162
Figure 6	Practice development triggers and action cycles	278

## Chapter 1

### 1.1 Summary of each chapter

<b>Chapter 1</b>	<b>Introduction</b> <p>Chapter one commences with the identification of the research aims and abstract. Section 1.3 describes the researcher's background, experiences, perspectives and beliefs. The purpose of this section is to provide an appropriate and comprehensive understanding of the researcher's experience, skills and perspective at the commencement of this study, enabling the data and analysis presented within the thesis to be read within this specific context. Section 1.4 provides a brief overview and sets the scene for the research. Section 1.5 provides a diagram of the phases of the research and the final section provides a list of commonly used abbreviations and acronyms.</p>
<b>Chapter 2</b>	<b>Literature review</b> <p>Chapter two includes the literature reviews conducted for this research. Sections 2.1 and 2.2 provide background literature review about the development of and current issues in dementia care and palliative care respectfully. Theories of person centred care and relationship care are debated in the context of the experience of dementia. The purpose of including this literature is to set the context of this research within the distinct subjects of palliative care and dementia care. Section 2.3 reviews literature specific to this study namely palliative care for PWAD, identifying key issues, developments and areas of need. Further literature reviews are included in chapters six and seven in relation to the topics of the action phase of the research; supporting family carers and the assessment of distress.</p>
<b>Chapter 3</b>	<b>Research methodology and methods</b> <p>This chapter commences with a statement of the research aims</p>

	<p>and a section justifying the adoption of an action research (AR) approach for this study. Following this a series of key components of AR will be presented from literature and debated in the context of this study. The following key components of AR are included: methodological approach and development, participation and democracy, reflexivity, action research cycles, developing a baseline understanding, AR theories, validity and reliability, ethical considerations of conducting research with PWAD and their carers. The notion of first, second and third person enquiry will be explored in light of this study. Continuing through these discussions, justification for adopting a participatory action research approach for this study will be presented. The chapter concludes with a description and justification of the methods used in this research. Action research is a complex process with many issues to consider. In respect of this, a degree of detail and argument is presented within this chapter in order to provide explanation and justification for the decisions and actions taken during this study</p>
<b>Chapter 4</b>	<p><b>Dementia palliative care needs assessment</b></p> <p>This chapter will describe a research process that was initiated to meet the first aim of the research, namely: to identify the palliative care needs of people with a dementia and their carers in West Lothian. Literature and evidence regarding the conduct of a needs assessment will be presented. This chapter presents a distinct and complete research process incorporating the following areas: identification of the aims of the needs assessment, definition of terms, inclusion criteria, recruitment, consent and confidentiality processes, data collection methods, analysis process, presentation of needs assessment priorities and utilisation of needs assessment priorities.</p>

<p><b>Chapter 5</b></p>	<p><b>Developing a baseline understanding of participating services and understanding their beliefs and values</b></p> <p>This chapter describes a phase of the action research where the researcher began to work with participating services, with a view to understanding the aims of their service, and how it was provided. This activity was a necessary precursor to identifying and introducing a change to practice, as it enabled a realist appreciation of the service and staff. Data collection methods and findings are described along with a collaborative feedback and analysis process. The chapter identifies the agreed focus to be taken in the next action phase of the research and the researchers' reflections regarding this process.</p> <p>Following this, commencing in section 5.11, a phase of the research will be described where participants were engaged in focus groups to determine their beliefs and values about supporting family carers of PWAD (Meadow Day Centre) and the assessment and management of pain for PWAD (Almond Ward). The findings will be identified along with their implications.</p>
<p><b>Chapter 6</b></p>	<p><b>Action phase: Assessment and management of distress and pain for PWAD: findings and analysis</b></p> <p>This chapter will commence with a literature review about the subject of assessing and managing pain and distress for PWAD. The chapter then presents findings and analysis that arose from work in Almond Ward. The findings and analysis are presented in regard to two key themes: first in section 6.1 the complexity of identifying distinct causes of distress and pain for PWAD who have communication difficulties and secondly in section 6.2 the implementation of the Disability Distress Assessment Tool in this continuing care setting for women with severe dementia.</p>

<b>Chapter 7</b>	<p><b>Action phase: Supporting family carers of people with a dementia: findings and analysis</b></p> <p>This chapter commences with a literature review about the subject of understanding the experiences of carers and how to support them. This chapter presents findings and analysis that arose from the research conducted in Meadow Day Centre. The findings and analysis are presented in regard to four key themes. In section 7.2 practice development in carer assessment and support, section 7.3 factors that restrict access to support for family carers, section 7.4 needs of carers are hidden to service providers and remain unmet and finally in section 7.5 Meadow Day Centre's influence on local health and social care dementia services.</p>
<b>Chapter 8</b>	<p><b>Conclusion and discussion</b></p> <p>This chapter focuses on addressing the original aims of the research, identifying conclusions in the light of research and evidence identified from the literature review. Dementia palliative care priorities are identified from the completed needs assessment process. Conclusions are identified in relation to the assessment of distress and pain and supporting family carers of PWAD. Throughout the chapter conclusions will be discussed in light of available evidence. The chapter concludes by considering the implications of this research for practice development and service delivery.</p>
<b>Chapter 9</b>	<p><b>Recommendations</b></p> <p>This final chapter presents recommendations from this research in regard to general palliative care for PWAD, the assessment and management of distress for PWAD and supporting family carers.</p>

## **1.2 Research Aims**

1. Identify the palliative care needs of people with dementia and their carers in West Lothian.
2. Describe and analyse two dementia care services in West Lothian as they develop their palliative dementia care practice: specifically the assessment and management of pain and distress for PWAD (Almond Ward) and supporting carers of PWAD (Meadow Day Centre).
3. Analyse the learning that occurs between dementia care practitioners and a facilitator experienced in palliative care during this action research.
4. In relation to the assessment and management of pain and distress for PWAD and supporting carers of PWAD, determine potential future implications for practice development and service delivery.

### **1.3 Researcher's background and perspectives**

It is my intention that by telling my story, at the beginning of this thesis, it will provide a basis, context and perspective of 'me', that will clarify the clinical experience, skills and values I bring to the conduct of this action research (AR). My aim is that this will provide an understanding of the perspectives and positions taken throughout this study. A number of authors highlight the essential and critical role of the researcher within AR (Hope 1998, Meyer 2000, Wadsworth 1998). AR is conducted through this person therefore it is primarily an interpersonal activity, less focused on methodological issues (Meyer, 1993). To a large extent, the quality of the research is directly dependent on the skills, knowledge and experience of the researcher. Their ability to challenge, support, discern, facilitate and reflect require understanding therefore it is crucial that those reading the research have a solid and comprehensive understanding of the researcher themselves (Rolfe et al 1995, Badger 2000).

#### **Development of interest in nursing**

In my last two years at school the notion of entering a caring profession came to the fore of my thinking. My education up until fifth year at school was based on arts subjects; history, geography, art, and english. I had deliberately moved away from all the sciences as I found them more difficult to understand, and less interesting. In my sixth year I made some radical changes and studied biology, anatomy, physiology and health and chemistry. I thoroughly enjoyed the health related subjects but couldn't really fathom chemistry at all; I managed to pass the exam by 'rote' learning passages from the textbook. My choices focused on becoming either a physiotherapist or a nurse. My girlfriend heavily influenced me at this time, she was about to commence training to become a nurse and was working temporarily as a carer in a care of the elderly setting. The stories of the people she worked with and her role in caring for them interested me and I felt that this was something I could do well. Working directly with people in a helping role appealed to me.

I was very unfamiliar with health care and nursing, I had never been in hospital and rarely had come across nurses in any setting. I was fortunate to have



experienced very good health, as did those around me. No one in my family was involved in health care and my family were surprised by my interest.

I had been a carer for brief, infrequent periods when my grandparents had periods of acute illness. I have distinct memories of these situations, they caused me concern and some distress but at the same time, when I was able to help, it felt good to be useful. These situations were emotional milestones for me as the acute illnesses experienced by my grandparents led to their deaths. I remember being struck by the importance and significance of these situations and thinking that those who cared for them were doing important work. I was aware of the grief of my mother following their deaths and the impact this had on her, my first encounters with death and bereavement.

To determine whether I would like to be a nurse, I did voluntary work at weekends for a year with older people in a geriatric hospital. I did this through my sixth year at school. Reflecting back, this was a fairly grim setting in which to be introduced to nursing and I was wholly and completely initiated into providing a wide range of care, which would be deemed highly inappropriate for someone of volunteer status today. Despite my naivety and shock at some of the intimate care nurses provided in their professional role and saddened by some of the sad sights I saw, I decided to train to be a nurse and abandon the notion of physiotherapy. A decision I have not regretted.

A further factor in my decision to become a nurse, unsurprisingly, was a fundamental belief in the importance of humans helping other humans. This now sounds somewhat trite and altruistic but does acknowledge an important driving factor in my thinking. I would consider that the source of these beliefs rest in the shared values of my family and a live, active Christian faith. Through reflection on these issues and writing this 'story,' I would acknowledge that these fundamental beliefs have not altered during more than twenty years as a nurse, however these beliefs now share a place with others, which have developed through experience. These include a concern for the future of nursing, a concern for vulnerable stigmatised groups of people who can't 'fight

their corner', measures of cynicism derived from a growing awareness of political agendas in health and social care, but paradoxically a vision for nurses to be more political, opinionated and develop positions of power and influence.

### **Professional development and continuing education**

In this section I intend to outline the training and education I have undertaken but also highlight particular experiences from practice, which I consider have contributed to my interest in this research about palliative dementia care.

I completed training as a Registered General Nurse in 1987, much of this training was undertaken at Edinburgh Royal Infirmary and I would consider my hospital experiences to be those related to providing care in a very traditional, hierarchical institution. Aspects of the training, which I remember, were lectures in 'terminal care', I was very interested in this as it seemed a new but neglected area of care and it's holistic nature really struck a cord with me. Within the routine experiences of nurse training I had provided care for patients who were dying. I had found this very hard and felt fairly inadequate in these situations but also struggled to know what to say or do. Despite these concerns, I did feel it was important work, which for a variety of reasons many staff avoided within the acute hospital setting.

I completed training as a psychiatric nurse in 1991 and worked for a year in a forensic unit within a psychiatric hospital. This unit provided care for people who had chronic mental health illnesses and who exhibited behavioural problems. During this experience, I learnt about assertiveness and consistent management of people who exhibited disturbed behaviour as a result of severe mental illness and who had become the product of institutional care. I also became very conscious of the impact of environment on people within a caring situation. The unit was in poor repair, a dark locked environment where little personal space was available for clients and common rooms were 'hospital like' in appearance. There was also little resource and facilities for organising rehabilitation activities. The stigma associated with mental illness was a

continuing barrier to providing care, for example the ward had no input from volunteers and minimal contacts with those within the local community.

Following this experience I followed my interest in terminal care and went to work in a hospice caring for people with cancer. I remember being astonished at the excellent facilities, the amount of staff that were available and the huge numbers of volunteers who worked there. In particular I remember opening a linen cupboard and seeing a massive number of large, fluffy Marks and Spencer's bath towels. In my previous post I was used to 'sometimes' being able to provide paper-thin, rough towels embellished with the hospital logo. The contrasts between the locked psychiatric ward and the hospice were immense. Issues of stigma associated with mental health services and the differences in service provision between the voluntary sector and the National Health Service became evident to me.

A memorable event, which occurred during this time at the hospice, related to the care we gave a man who had a glioblastoma, a form of malignant brain tumour. People with this problem can present with confusion, disorientation and psychiatric symptoms for example hallucinations. In many respects a similar scenario to caring for someone with a dementia. This younger gentleman was admitted to the hospice and we went through our usual admission routine, he appeared vague but somewhat docile, his family stayed with him for quite a while after he was admitted. After we had given patients their tea that evening, I saw the gentleman walking along the corridor of the ward with his family, I noticed that they looked pretty agitated and angry. I had no idea what was wrong, but thought it prudent to approach them and find out. They had left him earlier that afternoon and had come back to visit him after having their tea. On the way back to the hospice they had passed him in their car, walking along the main road outside the hospice. He was wearing pyjamas and slippers, it was winter, it was dark and he was walking along a very busy road on the outskirts of Edinburgh. It took a great deal of effort to persuade the family to leave him at the hospice that evening, they were rightly disgusted by the standard of observation and care we had provided in what is claimed to be a specialist

environment. We had real problems providing care for this gentleman, a lot of which stemmed from our environment. He could walk out of the ward at any time and it became a major nursing task to keep track of his movements. Balancing the provision of care for him and the other patients on the ward, some of whom were terminally ill was very challenging. He was also not a 'popular patient', as he could be irritable, verged on aggression and required constant supervision. We used drugs to sedate him as he, his family and the staff were struggling to cope with the situation. Looking after this young man raised all sorts of questions for me and challenged our ability to care for people with these problems at the hospice, I used his case study on several occasions when teaching both internal and external staff and discussing confusion in palliative care. Caring for frail people who are confused is common in the hospice, caring for young, relatively fit, confused people successfully, needs professional skills and appropriate environmental conditions. This experience highlighted to me the limitations of hospice care for young fit people who experienced confusion.

I worked at the hospice for six years, the final year and a half was spent in a post, which developed quality standards for hospice care and facilitated audit. The post also involved conducting clinical trials specifically related to new forms of analgesia used in palliative care. This was my first experience of conducting audit and research and changing my focus to working with staff and enhancing local practice, something I found very challenging and rewarding.

Whilst working at the hospice, I studied part time over four years to gain a Bsc in Nursing Studies. There was a very strong palliative care element to this degree (6 modules). I really enjoyed studying and the challenges it posed, I felt I developed professionally during this experience as I was able to link work experiences and study. For example I completed a double module of the degree (titled guided study) and was able to conduct an audit of pain assessment in palliative care. The hospice was able to use this information in their development of their pain assessment practices.

In 1997 I commenced working as a palliative care nurse specialist in a district general hospital. I was part of a new and developing hospital support palliative care team. This was an advisory role for multidisciplinary hospital staff and involved holding a caseload of patients with complex palliative care problems, usually pain or other distressing symptoms. The aim was to provide direct support to these patients and the professionals looking after them, but also to develop guidelines and provide palliative care training to multidisciplinary staff. Undertaking audit activity of the service, provided a basis for expansion and the inclusion of further nursing and medical involvement. Ninety seven percent of the patients we were involved with had cancer. I became aware that palliative care patients with diseases other than cancer did not receive our support and in some circumstances, and for a variety of reasons, experienced a less than adequate service. I also became aware of the differences between specialist and generic palliative care. In many instances, when working with patients who do not have cancer I felt inexperienced and out of my depth, some information and approaches were transferable but there was much that appeared to me, to be missing. I particularly remember being involved in the care of a young man with Cruetsfeld Jacobs disease. My involvement lay in supporting his family, and as such, my interventions were closely aligned with my usual practices. I was very conscious however that I had a layman's view of his disease and could only offer limited information and advice.

During this time I also had regular contact with a psychiatric ward in the hospital and they would seek support for their patients who had dementia, whom they suspected may be in distress due to uncontrolled symptoms. I remember consistently feeling uncomfortable with my involvement on this ward as all assessment discussions were conducted through the nursing staff, the patient was usually unable to participate in an assessment. My advice would focus on appropriate management of analgesia or other medication, but I was very conscious of the risks involved in this without having completed my usual assessments. I was unable to use my ordinary 'toolkit' of skills to assess the patients on this ward and the ward staff, although knowing the patients and having skills in caring for those with dementia, were also missing a way of

consistently describing the distress their patients were experiencing. I became very aware, through these experiences, that there were definite gaps in the provision of palliative care for PWAD.

During this time I undertook a masters degree in cancer nursing at the University of Glasgow. One of the modules I chose to undertake was an investigation of palliative care for people with non-malignant disease; as a result of my experiences on the psychiatric ward, I undertook a literature review of palliative care for people with a dementia. This literature review highlighted many of the challenges mentioned above and the struggle specialist palliative care services encounter when caring for this client group. There were difficulties highlighted for specialist palliative care services when they attempted to transfer their skills from cancer care to dementia care. There were also particularly difficult issues relating to the environment of specialist palliative care services and how these could be used or adapted for people with a dementia. Only in the United States of America were people with dementia cared for in designated specialist palliative care units, this as a result of private healthcare provision. This literature review therefore raised questions of the suitability, not only of specialist palliative care services for people with a dementia, but also the provision and nature of specialist palliative care advice given to those who provide dementia care. The conclusion of this review focused attention on generic palliative care and the limited attention given to the development of palliative care within dementia care settings and amongst those who actually provide dementia care.

The research I conducted for my Masters degree was an action research study of the management of constipation for patients with cancer. This was a very gritty and down to earth topic but I was very concerned at the lack of diligent care provided for this problem and the appalling consequences of this for patients. Patients I encountered suffered horribly and unnecessarily from constipation and conducting this research was a way of addressing this issue. This was my first experience of conducting action research and the approach really interested me, particularly the manner in which it involved people and

brought research directly into practice. This experience affirmed an interest in conducting research and in particular research that was based in practice and could indeed influence practice.

In 2001 I returned to a specialist palliative care setting and took up a post as a clinical manager for nursing and allied healthcare staff in a hospice. I was very comfortable with many of the issues related to providing specialist palliative care within this service, but I had a great deal to learn about general management as I had not really gained experience of managing staff previously. The hospice went through a period of change both in terms of personnel and function, which was difficult for a stable and enduring group of staff to contend with. I also became aware of the challenges of middle management where some clinical needs were evident to me and required addressing, however this has to be balanced with other broader demands. Understanding challenges in care provision and providing evidence and arguments for change was the mainstay of the work. In relation to my current research, I can identify particular issues that were challenging for me during this period, which are now particularly relevant to my involvement in an action research project. These included managing change and motivating staff to engage in change processes, for example working with new external partners who monitored and directed our service (National Health Service Quality Improvement Scotland). I also had to address my need to do many things myself and learn to delegate and give responsibility and opportunities to other staff. Learning and working with the differences between operational and strategic management was a further area that required learning. During my last year in this post I worked hard on setting a strategic direction for the nursing and allied health professional staff within the hospice. This was a protracted and difficult process with numerous revisions and amendments. I could see value in setting the direction, both for me as a manager who had to prioritise and set targets, and for the staff to see where we were going and why.

Over the three years in this post, I developed a cynical view of the organisation with whom I worked which I found difficult to resolve. The senior manager

consistently pushed for change, some of which was radical and involved staff losing their jobs and having to change their roles. As time progressed I came to believe that change, of whatever nature, was regarded as improvement and innovation and therefore to be commended. Staying and doing the same things was equivalent to poor, uncreative management. As I saw changes taking place, which I could not reconcile to be positive, and in my view, were linked to financial pressures and a need to be seen to be changing, continuing in this post became difficult. I found myself in a disempowered situation where providing arguments and speaking out was consistently undermined and then felt a worthless exercise. There was a constant tension between stating and doing what you believed in but also 'watching your own back' as there was job uncertainty across the organisation.

### **Triggers that have led to undertaking this research**

I recognise a pattern throughout my working life of wanting to look at the whole view of things and address real issues, which are pertinent to practice. Initial interest in what was then known as terminal care, strongly focused on these issues. The challenges of how to provide holistic palliative dementia care continue this theme and I would consider this to be highly relevant area for collaborative research.

I think there are a number of experiences from my more recent work, which have highlighted to me the challenges of undertaking collaborative action research. Namely; understanding the political and organisational forces at play, knowing whether people mean what they say, the sorts of changes practitioners will endorse and why, the need to develop strong arguments to support work, the need to be self-aware and understand the various perceptions of staff, managers, family and people with dementia and the need to develop open communication between parties involved in a project. Despite these numerous challenges, my past experiences have reinforced a need to conduct research that is both directly relevant and meaningful to practice but which is also highly collaborative in nature.



Enhancing the palliative care provided to people with a dementia and their families, strikes me as a relevant and useful issue to research. Research such as this could inform which areas of palliative care are seen as relevant to dementia care and what are useful ways, in our current climate, of enhancing palliative care within these services. From the perspective of specialist palliative care, this research could provide direction in terms of their service provision and involvement in practice development work. There could be potential to share expertise and evidence that could benefit both parties.

To summarise this section, there are key aspects of my experience, skills and knowledge that absolutely require understanding to ensure the following research account is understood in both context and perspective. Knowledge of palliative care, being a manager, initiating change and an understanding nursing from years of experience and from different perspectives. A strong awareness and desire to work collaboratively and encourage participation are the result of previous experiences of change alongside appreciating the value of facilitating others to enhance their development and practice.

#### **1.4 Brief Introduction to research: setting the scene**

This research was undertaken following a successful bid to the Big Lottery Fund by health care staff based in West Lothian. At the point of the research commencing, two significant dementia care organisations had highlighted a need to promote a palliative care approach for PWAD (Alzheimers Society, 2004). They recognised that PWAD were receiving inappropriate treatments such as the insertion of feeding tubes, as a result of practitioners not recognising the palliative nature of some situations. There was a sense that service providers needed to have an increased understanding of the palliative nature of dementia.

Specialist palliative care practitioners were also developing a growing realisation and interest in this area and there was a movement to focus on enhancing a palliative care approach within generic services, including guidance about PWAD. The Liverpool Care Pathway (Ellershaw and Wilkinson, 2003) and the Gold Standards Framework (King et al, 2005) were two important examples of this. As the research was underway the umbrella body for palliative care in Scotland produced a publication that specifically identified dementia as a disease that was life limiting and appropriate for palliative care interventions (Scottish Partnership for Palliative Care, 2006).

Other organisations were also developing national guidance about dementia care, this began to raise the profile of dementia more generally (Scottish Intercollegiate Guidelines Network, 2006). The Scottish Executive produced a template for delivering dementia services in 2004, which further promoted activity in reviewing the delivery and co-ordination of services.

In terms of the local situation in West Lothian, they were ideally placed to take forward an initiative focused on palliative care for PWAD. Community Health and Care Partnerships were being established whereby social and health care services would be managed together and there were strong, proactive and established teams within the fields of dementia care and palliative care that

could support this initiative. Furthermore there were individual practitioners actively seeking to be involved in the initiative.

From my perspective, as the person conducting the research, I had a range of experiences working in palliative care, I had trained as a mental health nurse, undertaken research and had a growing interest in action research, the planned approach for this study. These seemed an appropriate and relevant skill set to take the project forward.

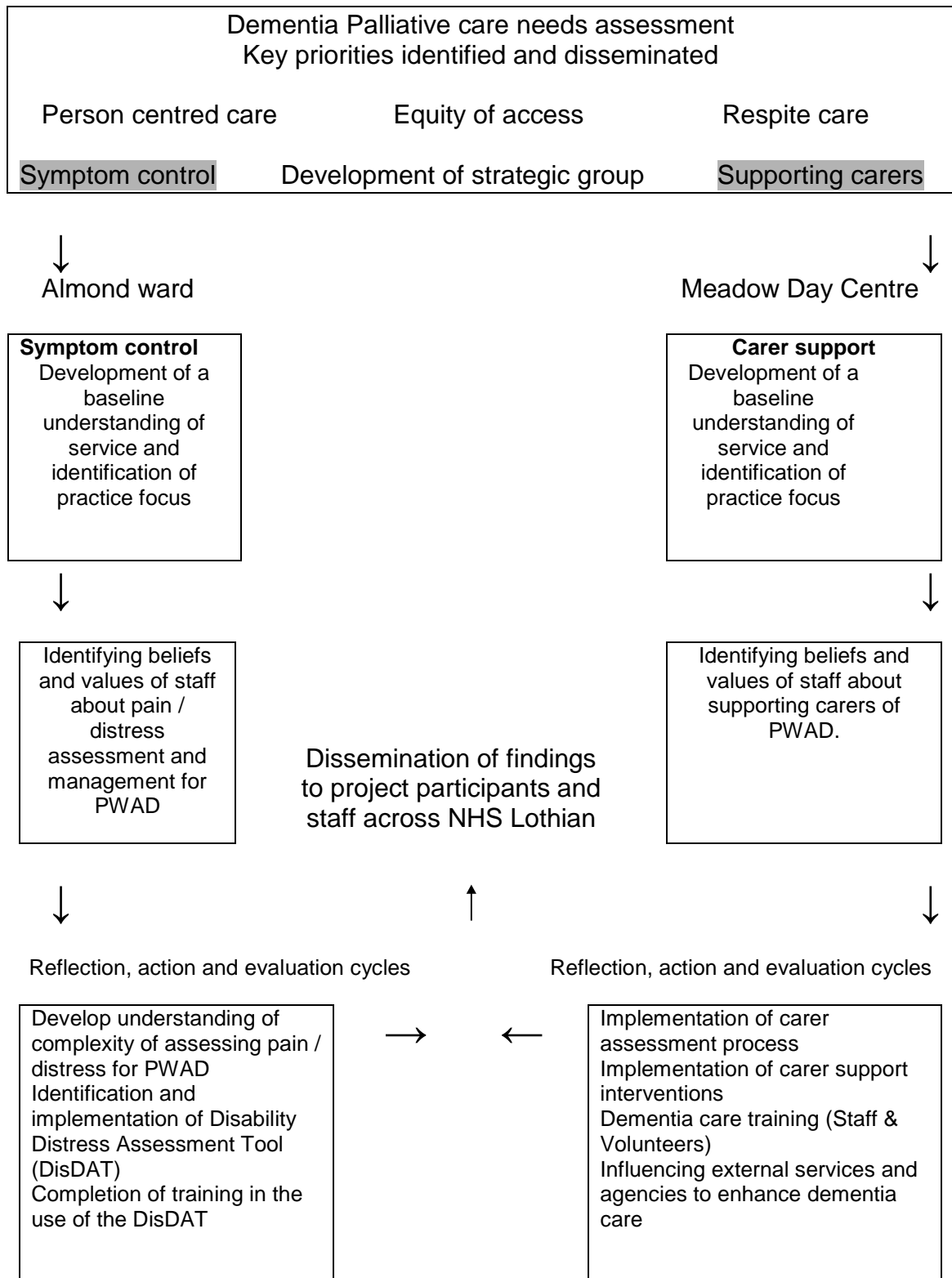
Taking all of the above factors into consideration, it was an opportune time to commence a study focused on the day to day realities of palliative care for people with a dementia.

## **1.5 Phases of the research**

Figure 1 provides a diagram that outlines the phases and cycles of this action research. The diagram illustrates that the research commenced with a needs assessment process involving PWAD, carers and service providers. The research adopted a relationship centred care approach, therefore throughout the thesis, data has consistently been gathered from these groups. The needs identified from this data provided the basis for the action phase to follow. Services that participated in the needs assessment, were approached to take part in the action phase, five services agreed to participate in the parent project and two of these are examined in depth within this thesis. The parent project is outlined and discussed in chapters three and five.

The aim of the action phase was that participating services would develop and enhance an aspect of their dementia care practice. From these developments the research would analyse the learning, which took place and consider the implications of this for practice development and future delivery of services for PWAD and their carers. Services identified their practice focus dependant upon: the outcomes from the needs assessment and the identification and agreement of their local service development needs.

In order to understand the service, its context and ways of implementing change, activities were undertaken to develop a baseline understanding of the service. Following this focus groups were held with staff where they discussed and agreed their beliefs and values in respect of their selected area of practice. The next phase involved cycles of reflection, action and evaluation specific to their local practice developments. This phase is deliberately described as cycles as reflection, action and evaluation occurred simultaneously dependent upon the stage of each development taking place. Practice development did not follow a linear process as several activities may have occurred at the same time but at different stages of implementation, therefore reflection and evaluation could take place simultaneously.



**Figure 1 Phases of the research**

## 1.6 List of abbreviations and acronyms used in the thesis

AL	Action learning
AR	Action research
CHCP	Community Health and Care Partnership
CPN	Community Psychiatric Nurse
CPNE	Community Psychiatric Nurse for the Elderly
CSBS	Clinical Standards Board for Scotland
DCM	Dementia care mapping
DisDAT	Disability Distress Assessment Tool
DS-DAT	Discomfort Scale in Dementia of the Alzheimer's type
GP	General Practitioner
GSF	Gold Standards Framework
ICIC	Improving Care Investing in Change
LCP	Liverpool Care Pathway
MSE	Multi sensory environments
NHS	National Health Service
PEACE	Palliative excellence in Alzheimer Care Efforts
PFI	Private finance initiative
PWAD	People with a dementia
RCT	Randomised clinical trial
REPDS	Revised Elderly Persons Disability Scale
RO	Reality orientation
SCAN	South East Scotland Cancer Area Network
SIGN	Scottish Intercollegiate Guidelines Network
SPPC	Scottish Partnership for Palliative Care
VT	Validation therapy
WHO	World Health Organisation

## **Chapter 2 Literature Review**

### **Introduction to literature review chapter**

This literature review chapter is presented in three sections. The overarching subject of the literature review is palliative care for people with a dementia (PWAD). In order to understand the context and the background of the research and literature in this subject area, the review commences with two sections that focus on development and current issues in dementia care (section 2.1) and palliative care (section 2.2) respectfully. Section 2.3 hones the literature down to the focus of the study and reviews research and literature relating to palliative care for PWAD.

As this action research study progressed and work with participating services commenced, the focus of enquiry was narrowed down further and two aspects of palliative care for PWAD became the specific focus of the action phase of the research. These were:

- 1) The assessment and management of pain and distress for PWAD
- 2) Supporting family carers of PWAD

Literature reviews related to the above two subjects will be presented in chapters six and seven. This is in keeping with the chronological nature of action research. At the commencement of the study these two subject areas had not been identified as specific areas for investigation. As the phases of the research progressed, the focus of investigation became apparent and further literature reviews were conducted in relation to this. These will be presented at the beginning of the findings and analysis chapters (Chapters six and seven).

During the period of this research, literature was searched on multiple occasions using the databases, Medline and Cinahl. Other literature, such as books, government documents and conference papers were searched by hand. Web based literature was also accessed. The following terms were used to conduct literature searches, these were used in a variety of combinations: dementia, Alzheimer's disease, dementia care, palliative care, palliative

dementia care, end of life care, pain assessment, pain management, distress, carer, carer support, carer interventions, family care, family support. Exclusion criteria included non English literature. As palliative dementia care is an emerging area of practice there was no restriction placed in terms of accessing literature within certain time periods.

Within this literature review, excerpts from case study data, personal reflections and references to service provision are included. The purpose of including these forms of evidence is as follows:

- To deliberately focus on practice related issues, as an aim of this research is to determine future implications for practice development and service delivery.
- To emphasise that issues identified within literature and research have specific relevance to current dementia care practice.
- To evidence both current gaps and research evidence utilisation in practice.
- To frame the context and position of this research in regard to current practice.

Including additional forms of evidence within this literature review also reflects the range of evidence gathered and presented within this action research.



## **2.1. Development and current issues in dementia care**

### **2.1.1 Dementia statistics and their implications for dementia care**

It is acknowledged that on an annual basis, the numbers of people affected by dementia in the United Kingdom, is steadily rising. This is due to the fact that dementia as a syndrome, predominantly affects older people and the number of older people is rising in proportion to the rest of the population. There are significant concerns that in the next two decades, there will not be enough people of working age to provide care for the large numbers of people who will be affected by dementia. Recent estimates state that there are currently 700,000 in the United Kingdom affected by dementia, this is expected to rise to 840,000 by 2010 (Alzheimers Society, 2006). NHS Health Scotland (p11, 2003) state, 'The baby boomers of the 1970's and 1980's will be in their 70's and 80's in the 2030's, and with lower fertility from the 1970's the overall population structure in Scotland is changing dramatically. Whilst greater longevity is also relevant, these broader demographic factors are the main reason why the projection for 2031 shows significant mass ageing.' Kitwood (1997) identified that the issue of rising numbers of people who have a dementia, is replicated in other countries where the society has been underdeveloped and has since become industrialised, identifying a global pattern.

These population changes are significant and will have a major impact on the delivery of health and social services in the future. As such dementia, as part of older people's care, can be viewed as a highly political issue where there is a sense of urgency to plan and develop responsive services (Scottish Partnership for Palliative Care 2006, Scottish Executive 2004).

It is important to consider that dementia does not only affect older people. People who have learning difficulties, and people who have alcohol problems are at a particularly high-risk of developing dementia. In particular alcohol related dementias are causing an increasing degree of concern, as the number of people with alcohol problems rises in Scotland. The number of young people drinking has risen and they are drinking more alcohol than before, there has

also been a 41% increase, over the last five years, in patients leaving general hospital with recorded alcohol liver disease (National Alcohol Information Resource, 2004).

In a similar way, obesity in Scotland is rising (Budewig et al, 2004) and recent research is linking obesity with the development of vascular dementia and Alzheimers disease. Alzheimer Scotland Action on Dementia (2006) report on a prospective study from Finland where 1449 randomly selected people were examined at five yearly intervals between 1972 and 1998. The study showed that when a combination of obesity, high blood pressure and high serum cholesterol level existed, the person was at 6 times greater risk of developing dementia, compared to those with normal weight, blood pressure and cholesterol. Alzheimer Scotland have used this research to raise awareness of healthy living in midlife as a strategy to reduce the risk of developing dementia.

Early onset dementia affects far fewer people than dementias in older age, however it raises significant issues in regard to the provision of services which meet the unique needs of younger people in their 40's and 50's who have a dementia. The appropriateness of existing day care and care home facilities for this group of people provides an example of such a challenge.

### **2.1.2 Historical development of dementia care (particularly the work of Chris Gilleard and Tom Kitwood)**

Kitwood (1997) argued that during the 1960's in the United Kingdom, the dominant approach to care of people with a dementia, followed a medical model. The focus being that dementia was an organic mental disorder and as such a medical, technical approach was adopted, which ignored broader human issues. Kitwood (1997) argued that these views were deterministic and negative, in that they framed dementia in terms of an increasing and ultimately fatal neurological impairment.

A further negative element to this approach reflects the absence of progress in medical treatment to minimise the effects of, or cure dementia. The lack of a

'magic bullet' at this time has marginalized dementia care further and as Higgs (2005) argues this failure in conventional medicine has continued to marginalize the speciality of Psychogeriatrics and in broader terms dementia care itself.

It could be argued that Tom Kitwood presented a negative, polarised view of dementia care during the period prior to the development of his own dementia care theories in the 1990's. Polarised in that he robustly rejected the established medical view and management of dementia in favour of person centred approaches. Some authors highlight the fact that person centred approaches had already been developing prior to Kitwood's work (Adams, 1996). These adopted a broader human view of dementia care which could be regarded as a precursor to Kitwood's theories, however these key writers were not acknowledged by Kitwood in his work (Morgan, 2005).

Seminal pieces of work regarding carers of older people, which adopted a broad, human approach were conducted by Grad et al in 1965 and by Sanford in 1975. These research studies were concerned with the lived experience of carers of older people and were not dominated by what Kitwood (1997) described as the standard paradigm or medical technical perspective. Their overall approach not only identified a direction for future research that aimed to understand the perspectives of this particular group, namely carers of older people, but also identified a need to further explore and act upon their human perspectives. It can be argued that these also represented further preliminary work undertaken ahead of Kitwood's theories.

### **2.1.3 The contribution of Chris Gilleard**

Most significantly the work of Chris Gilleard predated Kitwood's theories but had a strong influence on thinking around dementia care at this time. This work was strongly aligned to the moral standpoint of Kitwood, namely that the person comes first and that previous medical management had been detrimental to the experience of PWAD. Although Kitwood did not acknowledge the work of Gilleard, it is argued that this would have influenced the development of his

work (Morgan, 2005). Chris Gilleard was the author of a book titled; *Living with dementia*, first published in 1984. Morgan (p2, 2005) described this book as; 'raised intellectual adventure, opportunities for the imaginative, this book represents a frontier of the under researched area of dementia care.'

Gilleard's main contribution was identifying the experience of dementia as a social challenge, a personal tragedy and a clinical syndrome. Morgan (2005) states that at the time of publication these were new ideas where little else was offered. The impact of dementia on the individual was at the centre of the work, and this aided the reader to come close to the experience. Gilleard conveyed the meaning that; 'we live with dementia in the same way we live with destiny, risk and fear, dementia is personal,' (Morgan, p3, 2005).

Gilleard (1984) also went on to identify three core purposes of dementia care

- A need for security
- To minimize failure of self maintenance
- To provide adequate bodily comfort

These core purposes appear logical and provide a direction for care, however it is difficult to consider, now in 2008, that these issues were novel in their time as they appear so fundamental to what is written about dementia care now.

There are criticisms of Gilleard's work however, some related to its original outcomes and some in regard to how the work's relevance has stood over time. Higgs (2005) identified the following concerns; first the book has an absence of the perspective of users, namely people with a dementia and their carers. Today such an omission would be heavily criticised in line with user involvement strategies and a desire to understand a variety of relevant perspectives. Second the book presents a social construction of dementia from the sole perspective of professionals; this is linked to the previous point.

Gilleard did not reject a pathological model of dementia but aimed to raise the discussion and awareness of different people having vested interests in dementia and the provision of dementia care (Higgs, 2005). A key feature of

Gilleard's work relates to the social construction of dementia and the outcomes, which follow from this. Gilleard describes that dementia is socially feared because of the loss of self and personhood and importantly how others deal with these losses. To lose skills, abilities and function is distressing for the person and can also have a major impact on those around them. This key societal issue, termed as individual agency, is highly valued. Gilleard in 1984, argued that individual agency provided the basis for personhood in society. A tension therefore exists between society being able to seek and accept personhood in someone who has a dementia when they are losing their skills, ability and function (Higgs, 2005).

Higgs (2005) despite the above criticisms emphasises that through Gilleard's work, a different trajectory was opened, which acknowledged that dementia involves more than neurological changes but the loss of person or self. As we go on to describe Kitwood's 1997 work, it is evident that there are strong links with Gilleard's earlier work and one could be described as providing a potential springboard for the other.

#### **2.1.4 The contribution of Tom Kitwood**

Tom Kitwood has been a very significant figure in the development of dementia care over the last two decades. Kitwood studied natural sciences at Cambridge University then went on to complete an MSc in the sociology of education and then a PhD in social psychology. He worked as an Anglican priest and a chemistry teacher gaining experience teaching in England and Uganda. It is recognised that his interest in dementia arose from a friendship he had with an older lady who died of dementia in a social services home. The experience of observing the deterioration of his friend and her care was the catalyst for his dementia work. As his involvement with dementia grew he aimed to present a new paradigm of dementia care in which the person with dementia comes first. He was challenged by the prevailing social views that dementia can be described as a death that leaves the body behind and also the view that when older people go senile there is nothing you can do for them other than meet their physical needs. Adams (1996) described his work as the most influential in

regard to psychosocial approaches to dementia care and that his work was difficult to summarize due to its volume.

In his 1997 book, *Dementia Reconsidered*, he attributes many of the difficulties surrounding dementia care at this time to the adoption of a medical model of dementia, he was highly critical of a biomedical approach and how this approach reflected in the care and services people with dementia received. Kitwood reflected on the shock he felt when witnessing the treatment of people with a dementia, he observed people being demeaned, disregarded and what he considered to be the undermining of their personhood. A large focus of his work related to authentic contact and communication with people who have a dementia, work based on Rogerian psychotherapy. Kitwood (1997) described his approach as person centred care, he defined personhood as, 'a standing or status that is bestowed on one human being to another in the context of relationship and social being' (p8). To maintain personhood involved the following; 'when physical needs have been met, this is the central task of dementia care. It involves enabling the exercise of choice, the use of abilities, the expression of feelings and living in the context of a relationship' (Kitwood, 1997, p60). Adams (2005) states that Kitwood's work omits the embodied aspects of dementia, that dementia is experienced within and through the body and is not solely a psychosocial experience. Adams (2005) does however acknowledge that the notion of embodied dementia has developed after Kitwood's work and following his death in 1998.

A number of authors highlight particularly important points in relation to person centred care; that it does not fully acknowledge the effects of society upon the subjective experience of dementia and that there are significant societal phenomena such as race, gender and citizenship which contributes to the experience of the person with dementia (Adams, 2005). Person centred care focuses on the individual as the key player, Bartlett (2000) argued that this undermines broader change within society (environment and social barriers to empowerment) as change will be focused on individual interventions. In a similar vein, person centred care fails to acknowledge the important issue of

relationships, interdependencies and reciprocities that underpin caring relationships (Nolan et al, 2003). The theme from the above arguments is the challenges raised by the 'skewed focus' on the person in isolation, omitting to fully recognise the reciprocal impact of who surrounds the person with a dementia. There is a degree of irony in this statement, as so much of the development of dementia care has needed to focus on the person themselves, however the theories and discussion has now progressed from this initial basis. These concerns are acknowledged by others from a practice standpoint, Packer (2000) questions whether person centred care actually occurs in daily practice. Further discussion in relation to person centred care and relationship centred care will be included later in this literature review.

To serve as an example of person centred care, I will describe an example from data collected in this study but not referred to in the later analysis chapters. A resident of a care home was non-communicative and isolated himself from other residents; through discussions with his family it became clear that he used to be an accomplished mouth organ player. As the care home staff and family were concerned about his withdrawn state, it was agreed to give him a mouth organ and see what would happen. The man picked up the mouth organ and began to play it with both enthusiasm and skill, furthermore he appeared to clearly enjoy the experience. This was an important incident as it was an activity he appeared to enjoy, he received positive feedback from those around him and therefore a bridge to communication was identified, and it highlighted a skill he had, that was in tact, despite his dementia. As an approach it highlighted previous interests and activity, which were unique to him and therefore in line with person centred care. A person centred approach requires a focus and interest in individuals but also the practical application of this knowledge, at times a degree of creativity and flexibility is required. It represents the antithesis to care that is provided on a foundation of routine.

A further key theory developed by Kitwood (1997) was Malignant Social Psychology. He described this to be processes, which depersonalise a dementia sufferer. He took this theory to both a practical and consequential

level by stating that malignant social psychology could in fact worsen the neurological state of a person with dementia. Specifically he argued that the consequences of providing care that is impersonal, could actually increase the rate of neurological impairment and the consequent loss of function. The practical element of his theory was identifying methods of caring which embraced choice, preferences and individuality.

In order to clarify methods of caring that demonstrate malignant social psychology, I have taken a further example from the data gathered for this study. The data is again taken from a continuing care setting for PWAD. This refers to the use of the term 'feeders', to describe people who are unable to feed themselves and require assistance of care staff. When carers use this collective term during meal times this removes individuality and has the impact of grouping together individuals in respect of both a disability and a task. It is logical to consider the potential negative impact this may have on such clients over a period of time, particularly if this is one of a number of approaches to caring which lack insight and discernment regarding treating and caring for people as individuals.

Through Tom Kitwood's work and vision, the Bradford Dementia Group was established, the central aim of this group is the development of person centred care for people who have a dementia. A significant element of their work has been the development of a method of evaluating the quality of care within care settings, known as Dementia Care Mapping, this is discussed later in this chapter.

In a Scottish context, a similar organisation to the Bradford Dementia Group is the Dementia Services Development Centre at Stirling University. This centre similarly provides a focus to improve the understanding of dementia, provide consultancy, training and research services. During the period of this study a dementia centre, with similar aims to those described above, was also established in Ireland.



### **2.1.5 Critique of Tom Kitwood's contribution to dementia care**

In acknowledging and appreciating the contribution of Kitwood in the development of psychosocial dementia care, it is also necessary to describe the various and significant critiques of his work. The journal *Generations Review* dedicated an issue to critically reviewing living with dementia then and now where Gilleard and Kitwood's work was scrutinised. The writing that follows is predominantly taken from this issue of the journal.

There have been a number of fundamental concerns raised about Kitwood's research methods. Much of his research focused on interviews with carers of people with a dementia. Through these interviews he developed psychobiographies, and it was from this work he developed his dementia care theories. Adams (1996) describes his research approach as naive, he focused on the views of carers specifically and did not account for their particular perspective on events and experiences, their ability to accurately remember events from the past and that they, in some circumstances, may have provided incorrect information. Kitwood only published one such interview and could have done more regarding openness and transparency in his methods. Adams (2005) in a later review of Kitwood's work, reiterated the point that he could have done more to substantiate the developments of his theories by allowing public scrutiny of his methods and fieldwork. Whilst reading *Dementia Reconsidered* (Kitwood, 1997) the lack of research evidence and methodology is striking. Many conclusions are drawn from a few reflective stories, however whilst making this criticism, the conclusions and theories presented are logical and make sense, particularly in regard to addressing problems faced by people with a dementia. This point is acknowledged and developed by Bender (p129, 2003) who stated that, 'Kitwood's work is predominantly a moral and ethical approach rather than a verifiable theory'.

In my own analysis of Kitwood's work, a baffling element of his book is the use of mathematical type equations to present his theories. The equations do not help to clarify or support his theories and pose the question why it was necessary to use such an approach, was it to enhance the scientific nature of

his work by adopting a more traditional approach? This adds further confusion as he strongly rejected, and was critical of, a traditional medical paradigm, therefore why attempt to present his qualitative work using a quantitative form of numbers and equations?

#### **2.1.6 Considering Kitwood's theories of personhood in respect of person centred care and relationship centred care**

Other criticisms of Kitwood's theories have emerged over time; for example that his key ideas of personhood is poorly defined, as soon as you start to think about it, it is slippery and intangible (Killick & Allen, 2001). It could be argued that the application to practice of a poorly defined theory, such as personhood, is challenging. This criticism is worthy of consideration as Kitwood's theory of personhood was one he wanted to see lived out in the experiences of care for PWAD. The practical application of this theory into care was a desired outcome of Kitwood. Morris (2004) comments that a satisfactory definition and theory of person centred care is yet to emerge.

Person centred care has become an approach to caring in a variety of settings and for a wide range of patients and users of services, not specifically focused on dementia care. McCormack (2004) conducted a comprehensive literature review with a focus on person-centredness in older people's nursing, not specifically PWAD. He identified 110 papers, where the focus was on person-centred practice, most of these originated from the United Kingdom. The terms patient / person centred care are now commonly used within nursing literature and policy (Scottish Government 2008b, Scottish Government 2008c, NHS Lothian 2006, Binnie and Titchen 1999, Morris 2004).

McCormack (2004) identified that research into person-centred care, not specifically related to PWAD, has focused on the following areas: understanding the meaning of the term, application of person-centred care into practice and consideration of the context and culture of care settings when implementing this approach (Dewing 2004, Binnie and Titchen 1999, McCance 2003). It is evident that person-centred approaches to care are utilised and

evolving within many contexts of care as well as within the specific field of dementia care.

The criticisms of Kitwood's theory of personhood being ill defined as stated above, would appear to be undergoing development in a range of care settings. Interestingly this development of person-centred care practice has focused, albeit not exclusively, on older people. It is evident that progress with operationalising person-centred care has advanced with the work of McCormack and McCance (2006). They have developed a Person-Centred Nursing Framework, This framework is an important development in the context of understanding personhood and person centred approaches to care. This section of the literature review will deliberately focus on these issues.

The framework identifies four constructs, these include:

- Prerequisites, which focus on the attributes of the nurse
- The care environment, which focuses on the context in which care is delivered
- Person centred processes, which focus on delivering care through a range of activities
- Expected outcomes which are the results of effective person centred nursing

The development of this framework involved combining two distinct conceptual frameworks from each author (frameworks related to caring in nursing and person centred practice with older people), consideration of related literature and research and a series of critical dialogues with co-researchers and lead practitioners from a range of settings. The focus of developing person centred care, as identified through this framework, involves working on prerequisites in the first instance. This includes addressing issues such as professional competency and development of interpersonal skills. The progression of development then moves through the care environment construct to person centred processes. These include working with the persons beliefs and values, shared decision making and having a sympathetic presence.

The framework is comprehensive and appears to give a hierarchy and structure to what has previously been described as slippery and intangible. Reviewing the framework in terms of translation into practice, it is evident that it provides a focus for measurement and activity that would lead to providing care that would be person centred. A concern however relates to the language used in the framework and how this is understood by practitioners, interpreted in terms of person centred care and what this, 'looks like' in practice. This is the same concern, expressed above, in relation to Kitwood's notion of personhood. For example in the person centred nursing framework, within the prerequisites construct it is stated that a nurse needs to have an attribute of knowing self in order to provide person centred care. Knowing self is a complex notion. What does this relate to and how would a nurse be assured that they knew themselves sufficiently to provide person centred care? In essence the notion of 'knowing self', requires a framework in its own right to aid understanding and utilisation within a practice context. Knowing self could relate to physical, social, emotional and spiritual aspects. It is also possible that knowing self is something that changes and is affected by a number of factors such as mood, relationships and life events, it may not necessarily be something that steadily develops and progresses. Assuming nurses can know themselves to a suitable or appropriate degree, it is then challenging to consider how this notion is applied and discussed in routine practice. There is an inherent logic to nurses knowing themselves to some degree as this could provide the basis for providing care based on the patient's needs. Knowing yourself in some way acts as a baseline, starting point for understanding the needs of others. The development of the person centred framework for nursing provides useful constructs to work with, however the essence of developing a nursing framework necessitates clear and direct relevance / applicability to practice.

A puzzling element to the framework is the fact that the care environment construct comes after the prerequisites of the individual nurse. The aim of the framework is to reach the centre of the framework and deliver person centred processes and achieve person centred outcomes. It would seem more logical

to start with the care environment, then move to the requirements of the individual nurse moving to delivering person centred processes and achieving the desired outcomes. A number of the care environment elements could have an impact on the prerequisites of the nurse and logically it would be appropriate to address these first. For example one aspect of the care environment is identified as supportive organisational systems. If these were not in place, it could be argued that this could have a direct impact on the individual nurse's commitment to the job (an identified part of the individual nurse's prerequisites).

A further consideration of the person centred framework for nursing is how it relates to multidisciplinary ways of working within care settings. In many care settings there is a necessity to work collaboratively with a range of disciplines, each discipline potentially having its own focus and way of working. It is reasonable to suggest that there is potential scope and benefit for developing a person centred framework for care that incorporates a range of disciplines, not only for nursing. In this respect all disciplines would be working within a common framework and goal. This is especially pertinent when aspects of the framework incorporate issues such as decision-making systems. It is difficult to conceptualise that decision making systems would not involve other disciplines and as such already necessitate a degree of multidisciplinary working.

In terms of using the framework within care settings for PWAD, an operational issue arises of how to understand the views of PWAD in terms of the person centred processes identified. Shared decision-making, engagement and working with patients beliefs and values are key activities of person centred processes within this framework. PWAD will present with a range of abilities within care settings, for those with severe dementia, care staff may require additional support to successfully achieve these aforementioned person-centred activities. Understanding, for example, the beliefs and values of PWAD who have an advanced stage of the disease, would require the best, of what is described as excellent dementia care. As this literature review has identified, there are current concerns about the provision of quality of care for PWAD within care settings (Archibald 2002, Marshall 2001, Packer 2000). The person-

centred framework would appear to relate more appropriately to patients without cognitive impairment.

In raising a concern about the ability of PWAD who have advanced disease to engage in person centred processes, highlights a further question. How can a person-centred process such as this incorporate the views of family and people who know the PWAD? When verbal skills have diminished it is necessary for staff to gather information from others, however the person-centred nursing framework does not incorporate this activity. Moreover in order for care staff to understand the responses and needs of people who have advanced disease, there is a need to do this over time and as part of a working, caring relationship. Through this active, trial and error caring situation, those providing care can develop an understanding of the needs, pleasures and anxieties of PWAD. It could be argued that the complexity of this sort of nursing work is missing from the person-centred nursing framework.

In terms of exploring issues such as personhood and person-centred care, further relevant theories exist that require exploration. These are relationship centred care (Tresolini and the Pew Fetzner Task Force, 1994) and the use of the SENSES framework (Nolan et al, 2006). In this section a description of these two theories will be presented and then arguments relating to their relationship to Kitwood's person hood theories and the person-centred nursing framework (McCormack and McCance, 2006) will be articulated.

The SENSES framework emerged from work by Mike Nolan and Sue Davis and colleagues from the University of Sheffield and Northumbria University. The study arose from concerns about negative perceptions of nursing older people and this being regarded as a negative career option, the significant challenge of responding to the health care needs of older people and the lack of a framework on which to base older people's care. There was also an identified concern about the undergraduate educational experiences of nurses and their ability to effectively care for older people. As a consequence of these issues a research project was designed, the project was titled the AGEIN (Advancing

Gerontological Education in Nursing). The aims of the research were to determine the effectiveness of nurse education preparation in regard to caring for older people and their carers, to identify an epistemology of practice to guide education and to provide a therapeutic direction for nurses in day to day work.

The AGEIN project was a multi method, multi phase project. The conceptual phase of the study involved a literature search identifying empirical and theoretical literature. The empirical phase included detailed surveys with student nurses and staff to determine views about working with older people and their views on the situation of older people in the United Kingdom. Focus groups were held with students over a three year period involving four sites, visits to clinical sites identified by students as providing a good learning experience. A series of workshops were held with practitioners, older people and family carers in order to refine the emerging results.

The project also involved previous research undertaken by Davies et al (1999), which looked at dignity on the ward and investigated wards whereby their practice in relation dignity and care was regarded as positive. As a consequence of this data collection the SENSES framework was developed.

The data gathered for the AGEIN project involved surveys with 718 students and 1500 qualified staff, 67 focus groups were conducted over three years and visits to 33 clinical areas were conducted. The literature reviewed during the conceptual phase of the study involved detailed reading of 2,500 references. This study involved key participants, students, qualified staff, older people and carers. The sample was relevant and positively findings were refined with older people, carers and practitioners collectively. The numbers of participants involved in data collection was substantial and data was collected over an appropriate period of time (3 years). This is an important and study relevant to this thesis.

Analysis of the data highlighted the concepts of an impoverished environment and an enriched environment of care for older people. In the impoverished

environment student nurses experienced ageist attitudes and poor standards of care. This discouraged students from working with older people in the future. Conversely the experience of working within enriched environments of care, where students had positive experiences of older people's care, resulted in an interest in older people's care, and an appreciation of the stimulation and challenges involved in this work.

From the data gathered, the researchers were able to identify the elements of an enriched environment for older people and develop this into a framework for practice. The framework, known as the SENSES framework (Nolan et al, 2006), was identified from the perspective of student nurses. Within an enriched environment, student nurses would experience each of the six senses identified in Figure 2

A sense of security	Feel safe to explore the nursing role in an enabling and supportive learning environment
A sense of belonging	As part of the ward team, where the student is valued on the placement and encouraged to be part of things.
A sense of continuity	There are links between theory and practice, enhanced by consistent support from a named mentor.
A sense of purpose	That the student's own goals and learning needs were recognised by the placement and accorded some priority.
A sense of achievement	That learning objectives could be met and then the student could go on to explore other aspects of working with older people.
A sense of significance	That the student mattered and their contribution to the placement was also seen to matter.

Figure 2\*\*\* The SENSES Framework (Nolan et al, 2006)

Nolan et al's (2006) aspiration was that: 'The creation of an 'enriched' environment of learning and care, as defined by the SENSES Framework, has



the potential to transform students' views of nursing, especially in relation to older people' (p9). The appropriateness of the SENSES framework was tested out further, specifically with older people themselves, family carers and practitioners. Their relevance was acknowledged and supported. This finding meant that the six senses could potentially be achieved for each of these groups as part of an enriched environment care. Nolan et al's (2006) work identifies factors that would create the six senses for older people, family carers staff and students. For example to create a sense of security for an older person would include; staff being aware of your life story so that they really know you. To create a sense of security for a family carer could include; feeling safe to complain without fear of recrimination.

It is important, at this point in the consideration of the SENSES Framework, to identify the concept of relationship centred care. Nolan et al (2006) state that the SENSES Framework is more likely to be achieved within the context of a relationship centred approach to care. Relationship centred care will now be discussed.

A relationship centred approach to care was developed in the United States of America in 1994 by Tresolini and the Pew-Fetzer Task Force. It arose as a result of concerns about the growing numbers of people with chronic conditions and how modern healthcare, focused on cure, disease orientated and sub-speciality models of care, will cope with this situation. The results of this modern form of health care delivery, can result in fragmented and episodic care that doesn't acknowledge the wholeness of the person's experience (Clark, 1996).

The following extract states the vision of relationship centred care from the perspective of the Pew-Fetzer Task Force. 'In order to promote a more holistic vision of healthcare, the task force focussed both on the social, economic, environmental, cultural and political contexts of care, and on the subjective and inter-subjective experience of illness, and the relationships that unfold between practitioners, patients, families and the wider community. They argued that

these interactions lie at the heart of relationship centred care and are the foundations of any therapeutic or healing activity,' (Nolan et al, p123, 2006).

The Task Force were critical of modern health care in that, its organisation and focus were driven by efficiency and a scientific paradigm that is inadequate in understanding the experience of people experiencing ill health. The Pew-Fetzer Task Force (1994) at this point realised that the concept of relationship centred care was emerging and significant educational changes were required to support this approach to care. Importantly they had a focus on a balance between understanding and involving all those involved in healthcare such as staff, patients, family carers and students. This focus is aligned to Nolan et al's (2006) work whereby the SENSES framework could be applied not only to student nurses but to staff, patients and family carers also.

Nolan et al (2006) in their report of the SENSES Framework identified authors who expressed criticisms of the SENSES framework. Dewing (2004) expressed concerns about buzzwords such as person-centred care, although they make 'sense' and have an appeal to practitioners, as they are consistent with altruistic values, they do not sit comfortable within performance driven health care systems. McCormack (2004) is also critical of relationship centred care in that it only addresses one of four dimensions of Kitwood's (1997) notion of personhood, namely being in relation. It does not address the other three dimensions of being in a social world, being in place and being with self. Nolan et al (2006) however argues that when relationship centred care is taken into consideration with the SENSES, all four dimensions are addressed.

In terms of arguments promoting person centred care and relationship centred care, Nolan (2004) argues that respect for personhood is essential however this needs to be balanced and not privilege individual need alone. 'Relationship centred care in conjunction with the SENSES Framework makes explicit the importance of acknowledging and seeking to address everyone's needs in a way that person centred care does not' (Nolan et al, p131, 2006).

It could be argued that theories about relationship centred care are highly relevant to this study. Particularly in respect of connections between dementia care practice and approaches to palliative care. It was stated above that relationship centred care recognises a holistic approach to care, recognising equally all the players involved. It is feasible that the process of providing relationship centred care could enable palliative care principles to be embodied into practice.

Following the above discussion regarding the historical development of dementia care and dementia care theories, it is necessary to outline how these have impacted on care and describe the current situation specific to the context of the study in Scotland. The following section will discuss key developments and challenges in dementia care.

#### **2.1.7 Key developments and challenges in dementia care**

Through the identification and discussion of developments in care, an awareness of the challenges will also emerge and be incorporated within the discussion. Developments in dementia care discussed in this section include: care for PWAD in the acute care setting, reality orientation, reminiscence therapy, validation therapy, multi-sensory environments, social and diversional activities, environmental care issues for PWAD, drug treatment - Cholinesterase Inhibitors and Dementia care mapping (DCM)

From a personal perspective, I developed a need to understand dementia and dementia care when I commenced the post of Co-ordinator of the West Lothian Dementia Palliative Care Project. My background, as detailed in chapter 1, predominantly lay in palliative care and more specifically cancer palliative care. It had been more than a decade since I had spent time caring for PWAD, therefore updating my knowledge and understanding was essential. I undertook to read in this area and took opportunities to discuss this with new colleagues whose experience predominantly lay in dementia care and mental health. As my contact with dementia services increased, particularly non-specialist services, it became evident that what I had read was not generally practiced and furthermore there was a need for practitioners to understand the

knowledge I had recently gained. Care issues, which struck me as being logical and straightforward to implement, were either unknown, or known but not practiced.

A straightforward example of this relates to signage within care settings. Within a day centre and a care home I worked with, signs were evident which were inappropriate for people with a dementia. General principles of signage should be that writing and pictures should be used in combination, this gives the maximum opportunity to cue the person as to the meaning of the sign. Writing should be bold and a strong contrast should exist between the writing and the colour of the background, for example black writing on a yellow background is identified as the easiest to read, particularly for people with visual acuity problems. Signage should be at eye level, and in care settings for older people this needs to be carefully thought through. What I experienced in practice were signs where computer graphics had been used incorporating multiple colours and images. This demonstrated no awareness of visual and perceptual difficulties PWAD may experience. In the care home signs hung from the ceiling and appeared to be printed in a handwriting style. This signage was placed too high for the residents to see and potentially was not bold enough for them to read. Poor signage can cause specific problems for PWAD, for example incontinence, if a toilet is not clearly identified and therefore not easily accessible.

In conclusion, I was struck by the gap between what was written about dementia care and what I witnessed in practice. As this research progressed, this was a consistent issue and required direct action in the form of training, the modelling of communication skills and other interventions. Many of these issues appeared logical, straightforward and in my estimation, not difficult to implement into practice, therefore the question arose as to why this had not taken place.

## Caring for the PWAD in the acute hospital setting

Dr Carol Archibald in her work at the Dementia Services Development Centre at Stirling University, has written about the difficulties experienced by people with dementia in acute hospital settings. The busy, clinical atmosphere and the unfamiliarity of both the setting and the myriad of people encountered within a hospital can be very challenging for PWAD. Fundamental aspects of care can be missed as staff lack the knowledge of both the individual and the approach to providing person centred dementia care. Person centred dementia care can differ drastically from routines of nursing care in acute hospital wards (Archibald, 2002).

An example of this provided by Archibald (2002) relates to difficulties, which may be encountered by PWAD during meal times. Within the acute hospital setting, a tray with a meal on it would be placed on a table in front of the person with dementia, after a period of time, domestic staff seeing that the meal was not touched by the patient, then remove the tray. Should this scenario continue on a few occasions, the patient can quickly become dehydrated and malnourished and the problem, which initially brought them into acute hospital care, can rapidly become exacerbated. People with moderate to severe dementia may have real difficulties understanding, that what lies in front of them is in fact their lunch, the triggers to picking up cutlery and starting to eat may have gone, the understanding of language may be limited and the varied and noisy distractions which surround them, may distract them from the task at hand. The consumption of lunch for a person with dementia in these circumstances requires an in-depth understanding of both their individual abilities and deficits. It also requires time, patience and a focus on the part of caring staff to overcome these challenges. It is easy to understand from this example of fundamental care, why within these busy, acute hospital settings, people who have a dementia may not fair well.

This indeed was the consistent picture of the local hospital I was attached to. Complaints were received from families of PWAD whose care experience had

been fraught with difficulty resulting in poor care outcomes, such as dehydration, delirium, and their family member going missing from their ward.

Archibald (2002) highlights the need for acute care staff to identify dementia as a high risk factor, particularly due to the fact that the person will be unwell or have a specific problem, which has brought them into hospital and may compromise further their existing abilities. It could be argued however, that the direction of acute hospital care and the focus on initiatives such as preventing delayed discharge and waiting list initiatives, increase the focus of getting the patient in and out of hospital as quickly as possible and in itself may compromise the situation for PWAD who need more time and support than patients who can care for themselves independently.

Mary Marshall, former director of the Dementia Services Development Centre at Stirling University, when commenting on research which criticised hospital and nursing home care of PWAD stated, 'It would not be helpful if the response to this research was simply to pillory staff who are barely coping now, or to say it's society's fault for not providing resources. The responsibility lies with managers, doctors and senior nurses, commissioners of care and those responsible for standards. Good practice does exist and can show us what can be achieved within existing resources. The fact that it is not commonplace should concern us greatly' (Marshall, 2001).

In terms of the local context of this research, Lothian, the care of older people in general had been criticised with a few key cases being highlighted in local newspapers. A need has been established to develop older people's care, and in particular individual, person centred approaches to care. The former Nursing Officer for Scotland, Anne Jarvie, produced a report for NHS Lothian in 2006 where she emphasised the need to get back to basics and put the patient at the centre of everything nurses do. One of the recommendations of the report was, 'NHS Lothian should review how its commitment to person-centred care is being implemented to ensure that there is a better balance between the

technical aspects of treatment and the overall caring experience of the older person', (NHS Lothian, 2006, p17).

### Reality Orientation

Kitwood (1997) described a number of past care practices, which attempted to enhance the experience of PWAD. He described the emergence of reality orientation (RO) in the 1950's as a positive development in dementia care practice. In essence the purpose of RO was to bring people back into a sense of normality, however the underlying principle and ethos was equally important, namely that there was value in trying to do something proactively for people with a dementia to enhance their experience. Spector et al (p206, 2000) stated that the early work of RO, 'marked the advent of the use of psychosocial therapies in the care of PWAD.' Prior to this dementia had been seen as a medical problem, which required medical interventions as a form of treatment.

In brief RO can be described as a continuous approach whereby all communication throughout the day is reality based. Classroom RO has the same principles but has a group dynamic, where individuals meet and engage in discussions, which are based in RO. Looking at newspapers and discussing current affairs, is an example of this form of classroom RO. A classroom RO approach commonly used in practice settings is the RO board. These boards detail the day and date and other relevant, current information. It could be argued that this approach has lost popularity as it focuses on potential deficits of people who have a dementia and may introduce an element of stress through questions, which test memory.

There are however challenges to delivering RO in a sensitive way which takes account of an individual's needs. There have been criticisms that delivery of RO can be mechanistic and negatively impact on people's self esteem when they struggle with this form of communication and process of re-learning (Spector et al, 2000). Reviewing the evidence relating to RO has shown mixed results and quality issues, regarding the size and randomisation of studies, has impacted on the development of the quantitative evidence base. Two issues arose out of

Spector et al's (2000) systematic review of the evidence, first that the success of RO may be dependent on it being used at the appropriate time, by sensitive and experienced practitioners to receptive patients (p211). Secondly, evidence would be enhanced by the use of qualitative approaches alongside randomised clinical trials (RCT). This could provide an enhanced insight into specific features and issues regarding the provision of RO.

Within my clinical experience as part of this research, there are aspects of RO which have been broadly adopted, for example the RO board. The challenge however is to ensure that this is actively incorporated into what is happening in a care setting, for example do clients use it? Do they participate in completing it? Is it updated and current? Is the information included on the board relevant to the clients of the service? I have seen this used well as part of an activity at the beginning of a day within a day centre. I have also seen RO boards with out of date information, which is illegible in that the writing is too small for people to read. The message this portrays is negative, staff not paying attention to detail and therefore the process whereby a PWAD is assisted to be orientated, potentially becomes a further source of confusion and disorientation.

I have similarly witnessed both positive and negative interactions in regard to using RO in terms of an individual approach to enhance a person's experience. The honest, respectful sharing of experiences, where behaviour displayed by the person, indicated they felt cared for and valued. This was marked by a positive rapport between the client and their carer. In contrast the public questioning of a care home resident about the names of her three children felt testing and uncomfortable. What was there to gain in this exchange? The resident looked embarrassed, similar to a school child that had forgotten their homework. The approach lacked warmth and understanding and predictably, resulted in an emphasis of abilities now lost. I believe the motives of both practitioners were positive and based in an understanding of RO but the knowledge and skills of the practitioners were lacking.



## Reminiscence Therapy

Kitwood (1997) also identified reminiscence therapy as a positive development in the care of people who have a dementia. This involves the discussion and recollection of past experiences unique to each person and importantly is based on principles of respect and valuing each individual. From an individual standpoint reminiscence therapy can involve the person talking about their life experiences, family, friends, hobbies and work amongst other things. These discussions can be triggered and enhanced by looking at personal belongings such as photographs. A life history can be developed which can be an active document used by any person in contact with the individual, similarly memory boxes can serve the same purpose. In a group setting this work can involve discussion of past events, customs and places, where the emphasis is on shared experiences.

The key objectives of this approach are based on enhancing the quality of the person's present experience and to enhance the individualised nature of the care provided to them. It has been argued that this therapeutic work can provide greater insights into the person's current needs and aspirations (Johnson, 1976) and the process itself can highlight to the participant they are valued as an individual (Bartol, 1989). Gibson (2004) identified the values of reminiscence therapy for PWAD, to include retaining a strong and positive sense of self, retaining biographical memory, re-experience the feelings of happier times in life and participating in enjoyable, stimulating and creative activities.

Clarke et al, (2003) responded to concerns about the lack of person centred care by initiating a study, which used a biographical approach to enhance the care of older people. Findings from this study showed that working on life stories helped practitioners to see patients as people, to understand individuals more fully and form closer relationships with families. The staff also found it an enjoyable process to undertake which was also a positive outcome. A key aspect of reminiscence therapy is that the work is live and valued by those providing care. During data collection for this study a family carer expressed

her dismay when an auxiliary nurse approached her to complete a life history for her mother. The family carer had spent many months completing a life history document with her mother prior to her admission to the care home and had stressed to all the staff she came across that it would be helpful to read. The document was found on a shelf in the care home manager's office, reminiscence therapy needs to be a lived approach.

Care and attention needs to be paid to the attitudes and skills of those who undertake reminiscence therapy with PWAD. Gibson (1998) identified that this can be challenging work as the participant can experience a range of emotions as they go through this process. Respecting and valuing people as unique individuals, relating sensitivity and empathising are necessary skills and attitudes.

#### Validation Therapy

Feil (1992) developed this approach for people with a dementia. Validation therapy (VT) involves the following activities: categorising behaviours of PWAD into four progressive stages of withdrawal, a method of communication (verbal and non-verbal) and an approach for late onset disorientation, (Woodrow, 1998). The basic aim of VT is an attempt to understand and emphasise with the confused person's perceptions. It is not to provide insight or determine the facts of any given situation; the thrust of the therapy is to validate the person's feelings. Kitwood (1997) applauded the premise of VT as it highlighted the need to take seriously the experiences of PWAD and offered the potential for psychotherapeutic outcomes in dementia care. Based on humanistic philosophy, Woodrow (1998) states that the aim of VT is not to judge or analyse or hope to change the person, however claims have been made that improvements in behaviour can be achieved when this approach is adopted. A number of writers are critical of this claim (Woodrow 1998, Kitwood 1994, Scanland and Emershaw 1993) stating that the research completed by Naomi Feil in 1992 has been anecdotal and research analysis of VT has not identified any failures or limitations of the therapy. An open, rigorous analysis of data

would expect to highlight some areas where the therapy could be enhanced, or where limitations of the research methods, had impacted on results.

It is confusing however, to consider therapeutic outcomes and changes in behaviour as potential benefits of VT, when one of its aims, as stated above, is hoping not to change the person. A change in someone's behaviour may signpost something different about the person, for example a different way of perceiving something or feeling more relaxed than usual are potential examples of this. Perhaps this is, 'splitting hairs' about what Feil means when she states she is not hoping to change the person.

Throughout my contact with dementia care services during this research, I never heard anyone refer to VT. The only occasion where it was discussed, was during dementia care training provided by staff from the Dementia Services Development Centre.

#### Multi-sensory environments

Multi-sensory environments (MSE) is the term used to describe an area where pleasurable stimulation of the senses is achieved through the use of light, sound, smell and touch. This therapy was originally used for people with severe learning disabilities, for children experiencing chronic pain and more recently has been used for PWAD (Woodrow, 1998). This therapy is also known as Snoezelen and is commonly provided within a special room or dedicated area within a care setting. Sensory stimulants include smells from aromatherapy oil burners, visual stimulation by the projection of images on to walls and ceilings and the use of fibre optics. Vibrating cushions can be used as well as massage from a therapist to stimulate touch, music can be played or instruments used to produce pleasant sounds. A further factor to consider is that the client should lead a Snoezelen session not the therapist or carer. Ultimately the therapy is for the benefit of the client and their responses and interaction should shape what takes place. The aims of Snoezelen are to maximise the use of the senses and provide pleasurable stimulation bypassing cognition (Kitwood 1997).

The process of researching the impact / benefits of Snoezelen are challenging. Collecting data from PWAD who experience this therapy may in itself rely on observations of behaviour rather than verbal communication. Subjectivity and interpretation will be involved in this process and research processes will need to be open and rigorous to take this research issue forward. The multiple interventions provided during a snoezelen session may in themselves make the research difficult to evaluate. Woodrow (1998) makes an important point, in that during snoezelen sessions, a client will have the constant attention of a member of staff. Within care settings, this may be a rarity in itself and be the contributing factor to the client either benefiting or reacting adversely to the therapy. There are many variables to consider within research such as this. Unsurprisingly research studies that have been undertaken have been of a small size and therefore limit the impact of their findings. Specifically for PWAD Moffat et al (1993) found the following issues, PWAD were passive during the Snoezelen session, it was difficult to determine what brought pleasure, snoezelen could in itself be an imposition. Some appeared frightened and unsettled.

Despite the above problems the general issue of investigating what brings pleasure and benefit to PWAD is important. On an individual basis it could be very useful to know if a person enjoys a hand massage or the smell from an aromatherapy burner. In my view the use of alternative therapeutic approaches is important, if only that they provide another avenue to connect with and provide human contact to PWAD. They also have the potential to expand care beyond the provision of basic physical needs and by doing so provide carers with the opportunity to respond to the person as an individual.

One of the five services participating in this research has a Snoezelen room and patients use this during their contact with an activities nurse. The use of the room is very limited, the ward nursing staff very rarely take patients there due to other care commitments. Woodrow (1998) also highlights this point stating that having a specific snoezelen room can limit the provision of these types of therapies, as they seem confined and separate from routine care. He identified

a benefit for increased availability of sensory stimulation in all rooms and care areas.

#### Social and diversional activities

These types of activities include singing, quizzes, cooking, gardening and many more, too numerous to mention. Pulsford (1997) identified the aims of these to be encouraging activity, interaction and enjoyment. Essentially these are activities all people take part in and share to some extent, whether you have a dementia or not, as such they can be seen as normalising activities. They also offer the opportunity for people to use and maintain existing abilities and potentially enhance their self-esteem.

During this study I have regularly witnessed how music, for example, can have a powerful impact on people with a dementia. The apparently quiet, passive man attending the day care centre, coming alive when asked to sing one of his favourite songs and then receiving praise from his friends. This is an ordinary situation, but when sensitively facilitated by day care staff, the outcome was a positive impact on this gentleman's day. The lady who started to cry when hearing a song that meant something special to her and the lady who couldn't stand the volume of noise coming from a man playing the accordion, these are examples of ordinary life events and reactions. PWAD can become socially isolated as their illness progresses, therefore continuing participation in these forms of activities, can become increasingly important.

#### Environmental care issues for PWAD

There has been a great focus of enquiry into this aspect of care for PWAD. The Scottish Intercollegiate Guideline Network (2006), Guideline 86: Management of patients with dementia devotes a page of its content to environmental care issues. The essence of this lies in how to adapt and use the environment where care is being given, to enable the optimal safety, familiarity and ensure a reduction of stress for PWAD. I have mentioned above the issue of signage within care settings and this serves as a good example of simple measures

which can be taken which serve to clarify and give positive cues to PWAD (Day et al, 2000).

There are principles for dementia care environments such as, small, homely units (Vallelly et al, 2006) with higher levels of light and good use of available daylight (Poole, 2006). A person should have their familiar belongings around them and outside areas should be safely accessible and designed in such a way as to encourage access to outside spaces, socialisation and engagement with the environment (Hinman and Heyl, 2002). Contrasts of colour are important for example between the floor and the walls to help distinguish walking areas and prevent falls.

Technology is becoming increasingly important within care settings either in the person's own home, or other care settings. An example of this technology is a mat placed on the floor by a person's bed, should the person get up during the night and stand on this mat the toilet light automatically switches on, guiding them and providing a cue to the toilet. These are simple but important innovations, which can enhance safety and potentially allow someone to remain at home for a longer period than may have previously been feasible. There are many examples of such innovations which can enhance quality of life for the PWAD but also for their carers (Hagen et al, 2005).

As discussed above, I witnessed a number of environmental concerns within services participating in this research, which indicated a lack of awareness of dementia friendly environmental issues. In some circumstances the physical structure of the building did not appropriately lend itself to change, but other possible alterations were possible but omitted potentially as a result of lack of knowledge.

#### Drug treatment - Cholinesterase Inhibitors

The three main drugs used to delay deterioration in dementia are Donepezil, Rivastigmine and Galantamine. These drugs are known as second generation Cholinesterase Inhibitors and have only recently been available for use. Due to

this, there have only been limited trials, which have examined the drugs over a prolonged period of time (SIGN, 2006). These drugs act on the abnormalities in cholinergic neurones, which are present with people who have a dementia of the Alzheimer's type. The drugs are not effective for all forms of dementia, Donepezil is useful for Alzheimers disease only, Galantamine similarly is for use with people who have Alzheimer's disease but can also treat cognitive decline with people who have a mixed dementia. A mixed dementia is where the person may have Alzheimers disease and has suffered from cerebral vascular accidents with a resulting vascular dementia aswell. Rivastigmine can be used with Alzheimers disease and dementia with Lewy Bodies.

In Scotland the guidance from SIGN (p13, 2006) is that, 'there is support for long-term use of cholinesterase inhibitors to delay institutionalisation. The cost of additional community services is not taken into account in this study but savings in the cost of caring for patients in institutions may be substantial. This is a very important national statement and currently means that the drug is available for patients in Scotland who need it and meet the clinical criteria. From the perspective of quality of life issues for PWAD, it is relevant that the key issues identified in this statement are the impact on services and finance, the benefits to the individual and their experience is not mentioned. During 2007, further developments have ensured that any person who meets the clinical criteria for this drug can have it. Previously the budget for the drug was limited and a cap on the numbers of patients who could have it was in place, resulting in a waiting list and strict monitoring of patients to determine when the drug had lost its efficacy and should be stopped.

The cost of the drug has become a highly politicised issue within the health services in both Scotland and England. In Scotland the cost of the drug, after an initial period, becomes the responsibility of the General Practitioner (GP) and their drug budget. Previously it lay solely with memory clinics and hospital services linked to a psychiatrist. Managing the finite GP drug budget, in relation to the provision of cholinesterase inhibitors, is a serious issue. The decision-making processes and responsibilities are now spread across a wide range of

doctors compared to the previous system and control held by a memory clinic, and the decisions of one or two psychiatrists. Paradoxically despite agreement that the drug is now available here in Scotland, the new processes in place for administering the costs may instigate an inequitable and inconsistent service for PWAD dependant upon the individual budgets and perspectives of GP's.

In England the situation is different and the National Institute for Clinical Excellence has, after a five-year NHS study, decided that the drugs are not cost effective. They acknowledge that there are some beneficial effects for PWAD but recommends they are not prescribed for cost benefit reasons. The decision-making factors here, relate to the increasingly large numbers of patients with a dementia, the daily cost, reported to be £2.50 per patient and the perceived degree of benefit to the patient (Boyle, 2005). An uncomfortable, overarching issue, which this decision raises, is the value and consequent priority society places on older people and how this directly impacts on the care and services provided to them.

During 2006, we have seen decisions changed regarding expensive drug treatments for breast cancer. The political lobby from this group is very strong, both in terms of the emotional issues, which stimulate positive responses from key players and decision makers, but also this groups actual physical presence and collective voice within health care settings and political groups. PWAD and their carers have significant social, cognitive and practical challenges to overcome, in regard to this type of political lobbying, in reality much of the responsibility and activity lies with practitioners and groups such as Alzheimers Scotland: Action on dementia and the English equivalent, The Alzheimer's Society.

As a consequence of these new drug treatments, systems for diagnosis, assessment and management of dementia have been reviewed and there has been investment in services. In reality this has meant the development of services such as memory clinics, and the provision of support and information by specialist nurses and consultant psychiatrists. These are positive spin offs



for dementia care, particularly where there has been previous scarcity of service development. Significant decisions such as those from NICE could negatively impact on these developments.

#### Dementia care mapping (DCM)

It is worth including DCM as part of this discussion of key developments in dementia care, as DCM is a process which involves feeding back information to care staff with the aim of enhancing their person centred practice. Non-participant observation is the data collection method used in dementia care mapping (DCM). This process has been used as a way of measuring the quality of care and well being of PWAD in formal care settings. Designed by Kitwood and Bredin in 1992 it involves observing care and comparing this with predetermined categories. The process, amongst other things, is founded on a theoretical basis, which promotes personhood for people with a dementia. Care, which could be evidence of intimidation or objectification, would be scored negatively. This evaluation process has gained popularity in Great Britain and internationally (Beavis et al, 2002), however the process does not directly engage with PWAD. The underpinnings of DCM are regarded positively in terms of providing an evaluation framework for care given to people who have a dementia. There are some methodological criticisms however, such as the tendency for more severely impaired patients within formal settings to end up with lower scores due to their inability to interact, compared to more active patients in day care settings, who can communicate and interact spontaneously.

As with previous developments in dementia care discussed to date, DCM has not been implemented in any of the five services participating in this research and it has not been identified or discussed during the meetings and conversations which have taken place with participants.

### **2.1.8 Key messages from literature review**

- The increasing numbers of PWAD in the United Kingdom highlights a need to develop effective and responsive services, not only for PWAD themselves but for their carers also.
- There has been a significant focus and shift in dementia care to consider the impact of the illness on the 'person as a whole' and not only in terms of the treatment of a disease.
- Person centred care is a commonly used term generally and within dementia care, however as a theory it requires further exploration and application, particularly in terms of its impact on society's response to dementia, the skewed focus on the PWAD and lack of attention to those they are connected to, and the practical development of services and care.
- Relationship centred care and the SENSES Framework, as an approach to providing care, have potential value within dementia care. The focus on interdependencies and connections between PWAD, family carers and practitioners providing care, as well as social, environmental and political factors would appear to embrace the complexity and situational contexts of dementia care.
- Approaches have been developed, aimed at enhancing the quality of life and the quality of care of PWAD, such as reality orientation, reminiscence therapy, validation therapy and supportive environmental innovations. The evidence base for the effectiveness of these interventions is weak, due to the challenges of conducting research within this population.
- Clinical experience gained during this research has identified a gap in both knowledge and practice in regard to the dementia care developments identified above. This highlights a need to enhance practice by incorporating developments in care, where this is appropriate to both the setting and purpose of the service.
- There is also a need to conduct further research, which not only determines the effectiveness of dementia care developments but how these can be practically incorporated into services.



## **2.2 Development and current issues in palliative care**

### **2.2.1 Introduction to section**

The aim of this section is to describe and discuss research and literature regarding the development of and current issues in palliative care. It is important to describe fundamental palliative care issues in order to provide a context for the next section, a literature review about palliative care for people who have a dementia, the main focus of this research.

The section begins with a brief history of the development of palliative care signposting key events and milestones, definitions of palliative care will be clarified and the relationship between cancer care and palliative care explored. The rising focus on symptom control in palliative care will be discussed and then current activities to promote general palliative care will be presented. Section 2.2 concludes with literature and research focusing on the acknowledgement of a palliative care approach within care homes and key messages.

### **2.2.2 Development of palliative care**

It is understood that the modern practices of palliative care arose from the development of hospices (Saunders, 1998). Early medieval hospices welcomed strangers or pilgrims and provided care for them. The notion arose of hospices being places for those on the margins of society and the sick. Saunders (1998) argues that many would have had incurable conditions and would have received care until death with an emphasis on spiritual care. Hospices had Christian foundations and were run by catholic sisters or protestant organisations.

Most significantly St Christopher's Hospice in London, founded in 1967, was a key organisation involved in the development of modern palliative care. Dame Cicely Saunders was an integral part of this organisation and is renowned as a key driver in the development of palliative care. St Christopher's Hospice understood the need for and initiated research and audit to determine the

impact of their work. This represented the beginning of a palliative care evidence base. St Christopher's identified two key aspects of their work and captured these in the following statements, first; 'You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully but also to live until you die', (Saunders, pvii 1998). These statements squarely focus palliative care work on quality of life issues for people with life limiting illnesses.

Twycross (1980) identified how hospices' work developed and expanded, beginning with home care teams, which involved hospice staff working with people directly in the community. At the same time Marie Curie and Sue Ryder developed homes for cancer palliative care and non-malignant palliative care respectfully. This was accompanied by the development of palliative care teams or symptom control teams based within acute hospitals.

A further key British development occurred in 1987 when palliative medicine was recognised as a medical speciality. Palliative medicine is described as; 'the study and management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is the quality of life', (Doyle et al, p3 1998). Doyle et al (1998) emphasises however that this definition is specific to doctors specialising in palliative medicine and the term palliative care should be used when referring to the work done by a team of professionals who are part of a multi-disciplinary team, for example within a hospice setting. This development was key, in that it acknowledged palliative care in its own right and consequently required medical training to ensure the provision of available consultants, by necessity this also further embedded a research agenda in palliative care.

### **2.2.3 World Health Organisation definition of palliative care**

In 1990 an expert committee of the World Health Organisation developed the following definition of palliative care:

'Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of

psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anti cancer treatment. Palliative care

- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death; and
- offers a support system to help the family cope during the patient's illness and in their own bereavement.'

World Health Organisation Expert Committee (1990)

Key characteristics of this definition are that palliative care is applicable to any disease, which cannot be cured, not only applicable to those people who have cancer. Despite this assertion, there is a specific reference to anti-cancer treatment in the definition. This appears to be contradictory to the first statement in the definition and appears to assume cancer as the problem. The reason for this specific cancer reference is to highlight proactive palliative care in the form of palliative chemotherapy or radiotherapy, where cure is no longer feasible but active anti cancer treatment may assist with symptom control.

Palliative care is identified as a proactive approach and aims to take account of the whole person, the whole person being characterised by physical issues, (pain and other symptoms) also psychological, social and spiritual aspects. Its basis is that of a problem solving approach with the aim of achieving the best possible quality of life for the person directly affected and for their families.

The definition is clear in its position against euthanasia, palliative care refutes hastening death as a primary intent. It also makes reference to a support system, for both patients and families, it could be argued that palliative care, as

an approach, does not represent specific services or organisations, therefore the word 'system' as used in this definition is unclear. Who would be the providers of the system, who would be responsible for co-ordinating and managing such a system? There is strength and consistency however, in viewing the patient and the family as a unit, both requiring attention and care, this is consistent with a total approach to care identified within the definition.

In 2002 the World Health Organisation definition of palliative care changed, the following discussion describes the changes and their implications. The new definition takes a more affirmative stance about quality of life, stating 'improving quality of life for patients and their families', rather than, 'the achievement of the best possible quality of life', as described in the 1990 version. The term 'not responsive to curative treatment', in the original definition is replaced with, 'life threatening illness'. The new term can be described as more inclusive, in that it incorporates illnesses which may be life threatening from their onset, such as dementia, rather than only those whereby cure was originally possible. This would appear to cast a wider net for palliative care and a move away from a focus on cancer.

The 1990 phrase, 'Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount' is expanded to become, 'through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and social' (WHO, 2002). The new definition identifies a more proactive stance and emphasises the need for the highest standard of assessment and the notion of preventing problems before they arise.

The 2002 definition has some additional components such as the need for a team approach to address the needs of patients and families, and that a palliative care approach may in fact positively influence the course of the illness. My interpretation of this statement is that a person's life may be prolonged if their symptoms are well controlled and they are supported from a physical, psychosocial and spiritual perspective.

The issue in the 1990 definition, regarding the appropriateness of using anti cancer treatment alongside palliative care approaches, is expanded further in the 2002 version. It specifies therapies that are intended to prolong life, such as chemotherapy or radiation therapy can be useful in achieving improved management of distressing clinical complications. All of these are identified as appropriate interventions early on in a person's illness alongside a palliative care approach.

In summary the 2002 definition is bolder in its intent and provides more specific information about what palliative care is. There appears a greater confidence in what palliative care is about and an understanding and significance given to the issue of effective assessment. Importantly some word changes in the revised definition emphasise the applicability of palliative care to non-malignant, life limiting diseases. This clearly highlights that this approach is entirely appropriate for PWAD and their carers.

#### **2.2.4 Clarifying definitions of palliative care; A Palliative care approach, General palliative care and Specialist palliative care**

In order to understand and clarify how palliative care relates to dementia care, it is useful to clarify the above three terms, as they can be confusing for both lay people and professionals. The Scottish Partnership for Palliative Care (2006) produced statements, which aimed to clarify the differences between these three related terms.

A palliative care approach: is described as, 'a basic approach to caring for people which emphasises good communications and respect for an individual's autonomy and dignity. As mentioned above, it also recognises needs which are physical, social, psychological or spiritual or a combination of these,' (p10). The definition also states that this approach is particularly appropriate for long-term progressive conditions such as dementia. This approach can be adopted by anyone in a caring role. The author of this paper is aware that this definition is frequently debated, in that it merely represents, what is generally regarded as



good fundamental care, which anyone should receive, regardless of condition and whether or not that person is in a palliative situation. This is an important debate, which we shall focus on in the next section, when considering palliative dementia care, is palliative dementia care not just good dementia care?

‘General palliative care is care based on understanding and practice of palliative care principles, which focus on; quality of life, good symptom control, a whole person approach, care for the person and those that matter to them, respect for autonomy and choice and an emphasis on open and sensitive communication,’ (Scottish Partnership for Palliative Care, p10, 2006). An important element of general palliative care is that it is provided by the person’s usual carers, for example nurses, doctors, care assistants, within their own setting, for example at home or in a care home. In essence it is the practical application of a palliative care approach within the person’s own situation and provided by generalists serving their home situation.

Specialist palliative care uses all of what has been stated above but is focused on people with complex palliative care needs with a specific requirement for a multiprofessional specialist team. There are three specific team settings where specialist palliative care is provided; hospices, palliative care teams within hospitals and community palliative care teams. The Clinical Standards Board for Scotland (2002) developed standards for specialist palliative care, this was the first time there had been national agreement and standards set in Scotland, regarding the provision of specialist palliative care services. Specifically they identified which professionals should make up a specialist team, what qualifications they should have and how a team should work. The rationale for standardising the approach was that clients should receive a consistent standard of specialist palliative care regardless of which service they accessed. It could be argued that this was specifically necessary as hospices have different funding arrangements, some voluntary, some NHS funded and therefore differing management arrangements and service provision. The Care Commission followed up the work of the Clinical Standards Board for Scotland, by developing standards specifically for hospice care, usefully written from the

perspective of the client and what care they can expect to receive from a hospice.

### **2.2.5 Relationship between palliative care and cancer care**

Palliative care has grown alongside cancer services, specialist services such as hospices, care for only a small number of people who have non-malignant disease. In 1997 Eve et al analysed hospice and palliative care statistics in the United Kingdom for the period 1990 – 1995. They determined that at this time only 3.3% of patients with non-malignant disease were cared for in hospices and that in 1995, 17.5% of all UK cancer deaths occurred in hospices, representing 28000 deaths. Most recent statistics for England, Northern Ireland and Wales, showed that in 2006, 93.9 % of inpatients within 187 specialist palliative care units, had a diagnosis of cancer (The National Council for Palliative Care, 2006). In eleven years a rise from 3.3% to 6.1% of patients with a non-cancer diagnosis.

MacDonald (1998) clarified the need for cancer services and palliative care services to be bedfellows. He stated that over 7000 000 people in the world will die from cancer annually and that oncology research focuses on the impact of treatment on tumour burden and the effects of drug toxicity. A palliative care influence continues to be necessary to ensure examination of treatment in regard to pain and psychosocial issues. MacDonald (1991) determined there to be four phases of cancer prevention:

1. Prevention of the disease (public education and policy)
2. Prevention of advanced disease (early diagnostic programmes)
3. Prevention of death (anti-cancer treatment)
4. Prevention of suffering

He stated that cancer centres have concentrated on the first three and the lack of focus on the fourth phase has led the way for the development of palliative care alongside cancer care. This suggested model is concerning, particularly when prevention of suffering is considered the fourth and final phase. Is it not

possible that suffering can be experienced in all of these phases? To serve as an example, consider the daughters of a mother with breast cancer and the anxieties and decision-making relating to a potential genetic link, in MacDonald's model this is phase one but this is a form of suffering.

From a Scottish perspective, examining the name change of the national umbrella organisation for palliative care, further highlights the relationship between cancer and palliative care. In 1991 the Scottish Partnership Agency for Palliative and Cancer Care was established, as the name implies the agency was responsible for both palliative care and cancer care and the two were clearly linked. In 2006 this changed and the constituent members of the agency agreed a change in their name to the Scottish Partnership for Palliative Care (SPPC). Clearly cancer care was removed from the title, reflecting an increasing awareness and need to represent non-cancer palliative care issues. A tension does exist however, as specialist palliative care services drive forward palliative care issues within the SPPC but the remit has widened to a more inclusive agenda.

A similar scenario occurred with the sister palliative care organisation in England, Wales and Northern Ireland, their name changed from the National Council for Hospice and Specialist Palliative Care Services to the National Council for Palliative Care. In a similar way broadening the remit of the organisation to represent more than specialist services which, in reality, are also predominantly cancer services.

In summary, it is evident that palliative care has grown alongside cancer care, however in the last 10-15 years, a broader palliative care agenda has emerged acknowledging the needs of people who have a non-malignant life limiting condition such as dementia.

#### **2.2.6 Focus on symptom control**

A key activity of general and specialist palliative care is symptom control. It is one of the main reasons a person is admitted to a hospice or has involvement

of a specialist palliative care practitioner. Hospices, in line with other in patient units, have pressure in regard to length of stay and bed occupancy; therefore admission criteria are strictly focused on those with specialist need. In reality this means those with the worst symptoms, where non-specialist practitioners are struggling to relieve suffering. There is a concern that in recent years specialist palliative care practitioners are overemphasising this aspect of physical care and symptomatology has become the key function. Clearly assessing and controlling symptoms is of extreme importance but the concern focuses on the balance of this physical element in conjunction with psychological, spiritual and social aspects of the palliative care approach.

Hearn and Higginson (1998) conducted a systematic literature review investigating whether specialist palliative care teams improved outcomes for cancer patients. They reviewed 18 studies and determined that these teams were able to identify and deal with patients and families needs and there was evidence of improved pain control and symptom management. From an economic perspective, a positive outcome was also identified in that patients spent less time in hospital and were able to access support through community services. This evidence base has been strongly influential in supporting the development of specialist palliative care services in hospitals and both affirming and continuing the work conducted within hospices and palliative care units.

It is clear that hospices are required to work in similar ways to other in-patient units, as they are part of the structures of our health and social care services and therefore similarly need to maintain efficiencies and standards. It is not possible for patients to be admitted for several months in the dying phase of their illness, admission is for a specific reason and focussed on outcomes with the aim of using the resources effectively. With this said it is difficult to determine how diseases, other than cancer, can fit into this model of care, particularly those with more uncertain disease trajectories, where the course of the illness is over many years such as dementia related diseases. It would appear logical that the majority of care, for people such as this, would be provided by general palliative care services and not specialist services such as

hospices. Research by Addington-Hall and Higginson (2001) however focussed on palliative care for people with conditions other than cancer, specifically identifying the needs of PWAD and their carers. This research is indicative of a movement within specialist palliative care services to focus on non- malignant palliative care issues.

### **2.2.7 Activities promoting general palliative care**

There are a number of key strands of activity, aimed at improving the palliative care experience of people with life limiting diseases, that feature in the activities of specialist palliative care practitioners. At a local and national level there are the development of guidelines and standards. As previously mentioned the Clinical Standards Board for Scotland (CSBS) (2002), now known as NHS Quality Improvement Scotland, produced standards for specialist palliative care services. This had a significant impact on specialist services, as this form of standardisation and agreement on working practices had not been identified or implemented previously.

Other guidelines worthy of note are the Lothian Palliative Care Guidelines developed by the Lothian Palliative Care Guidelines Development Group (2006), a set of clinical guidelines developed by a multidisciplinary group of professionals from specialist palliative care and generalist settings. The guidelines are aimed at those practitioners working in non-specialist settings and are relevant to dementia care and other non-malignant disease. These guidelines have been adopted across many areas in Scotland and are available electronically. They have been well distributed across Lothian and are currently going through a revision and update. This revision includes new guidelines on pain assessment for people with communication difficulties. The author of this paper led a working group to develop this particular guideline. A criticism that could be made of the guidelines is that there has been no practice development activity associated with their implementation and utilisation. Experience gained from conducting this study identified that staff were aware of the guidelines but did not actively use them, despite the fact the information contained in the guidelines was relevant and useful to them. There are potentially many reasons

for this, one of which relating to the large volume of guidelines now available to staff and a potential sense of overload.

A further significant Scottish guideline is the Scottish Intercollegiate Guideline Network (SIGN), guideline 44 (2000), Control of pain in patients with cancer. This has been a key guideline impacting and involving palliative care and currently evaluation work is underway regarding how this is used in practice. Much of the focus of this work relates to the assessment of cancer pain.

There are another two key developments in palliative care that are focused on identifying best practice in palliative care and processes whereby this can be achieved in the provision of direct care. The Liverpool care of the dying pathway (Ellershaw and Wilkinson, 2003) is a care pathway for people in the dying phase of their illness. Its aim is to positively influence palliative care practice and fundamentally impact upon care for the dying in non-specialist settings. It is a multidisciplinary document, which incorporates evidence based practice and appropriate guidelines related to care of the dying. Very positively it makes practical what the other guidelines stated above have failed to do. By a multidisciplinary group of staff participating in the pathway it brings the essentials of specialist practice to non-specialist services and organisations. The pathway was originally intended for hospitals, to bring hospice care to the hospital setting but is now being used in care homes. This work has become a national palliative care activity and has also started to be used in other countries. Research conducted into this work has identified positive outcomes in care when the pathway is adopted but also the ability to audit and review practice. A key issue however is the support given to staff in using the pathway, in many instances it highlights a different way of working and challenges views and practices related to death and dying (Hockley et al, 2004).

The second key development is the Gold Standards Framework (King et al, 2005). 'This framework seeks to facilitate consistent and high quality community palliative care through a set of guidelines, mechanisms and assessment tools,' (King et al, p619, 2005). In a similar principle to the

Liverpool Care Pathway it brings together evidence and a practical way of working, however on this occasion it is focused on community care. The Gold Standards Framework (GSF) has been recognised at a national level and funded roll out programmes have recently taken place throughout the United Kingdom. To briefly state how the framework works it focuses on a three step model, first identify palliative care patients, second assess their needs and third plan care and support to meet their needs. This sounds very logical and straightforward however to achieve even the first step requires multidisciplinary discussion within a practice and this can require a shift in ways of working. The framework then focuses on the seven 'c's', which focus on issues such as communication, care co-ordination and control of symptoms. Research has identified a number of positive outcomes when practices have adopted the framework, patients don't fall through the net, patients feel reassured that a team of people are looking after them, understand their problems and are aware of a plan of care. Negatively there are concerns about increased paperwork and the burden of work that falls on the GSF co-ordinator, usually a District Nurse (King et al, 2005).

In summary the success and national acknowledgement of these two processes relates to the fact they have brought current palliative care best practice directly into clinical situations, both in the community and in-patient settings. At first glance they appear logical and straightforward and possibly even basic in their structure, however their benefit is the way they acknowledge all the other multiple demands placed on practitioners and allow them to focus on the provision of good palliative care. For example the LCP flags up mouth care, pain care and what issues to discuss with families, in essence practical prompts to good care which could easily be lost if left to individual practitioners. An interesting and positive feature of both of these processes is that they are not specific to cancer care and could be used for anyone dying in an in-patient unit or within the community. There is definite potential to utilise both of these developments for people with life limiting conditions other than cancer, in particular within the context of this study for PWAD and their families.

Whilst acknowledging these very positive developments, it is appropriate to state that they are specifically focused on end of life care, the accepted 'stomping ground' of palliative care. They do not tackle issues in regard to interventions earlier in the course of the illness. This is an important issue for dementia care, in particular understanding the wishes of the person whilst they have mental capacity, for example proactively organising a power of attorney.

### **2.2.8 Palliative care in care homes**

There has been a strong focus on care homes and the palliative care delivered to people cared for within these settings. Due to reduced in-patient beds within acute hospitals, and the specialist admission criteria for hospices, care homes are playing an increasing role in care of the dying and palliative care and therefore are becoming a central focus for palliative care research. Research has identified some of the challenges for care homes in providing palliative care, staffing levels, communication and support from General Practitioners, the level of involvement from community palliative care nurses are some of these challenges (Katz et al, 1999). The Scottish Partnership for Palliative Care developed national practice statements for general palliative care in adult care homes in Scotland (2006). These statements, although accurate and informative, are ultimately aspirational. There has been criticism that they challenge the care provided in care homes but no support has been established to enable care homes to achieve these statements. In the next section on palliative care for people who have a dementia, the care home setting will be a key focus of literature review, research and debate.

### **2.2.9 Key messages from literature review on development and current issues in palliative care**

- Palliative care has developed alongside cancer care and is interested in the person as a whole, including their physical, psychological, social and spiritual dimensions.
- Following a palliative care approach and providing general palliative care are synonymous with principles of person centred dementia care



- During the last decade, a general movement (organisational and practice development) has taken place that positions palliative care development with non-malignant disease. This is highly relevant for dementia care.
- Specialist palliative care services are targeted at cancer care
- Specialist palliative care services have developed and initiated models of care aimed at enhancing a palliative care approach within general care settings, for example the Liverpool Care Pathway for the Dying and the Gold Standards Framework. These developments are inclusive of providing care to PWAD and their families.
- Care homes have become a focus for the development of general palliative care.

The next section of the literature review will build on these discussions to determine developments in palliative dementia care, what it looks like and what is the focus of the literature on this subject.

## **2.3 Development and current issues in the palliative care of people who have a dementia**

### **2.3.1 Introduction to section**

In the previous sections 2.1 and 2.2, we looked at literature about the development of and current issues in dementia care and palliative care respectfully. The purpose of this was to set the stage for the background of this research, namely exploring what is meant by the notion of palliative dementia care. One of the aims of this research is to understand the palliative care needs of PWAD and their carers. It is necessary therefore to ask some key questions to explore the meaning of palliative dementia care. If we emphasise that dementia care is palliative, what benefit does this bring, if any, for PWAD and their carers? What particular aspects of dementia care does this affect? What new insights are gained from reframing dementia care as palliative care? Are there any wider social and political implications? What, if anything, can dementia care bring to palliative care?

In order to debate these issues, consideration will be given to what is written in literature about palliative dementia care. There will be a debate regarding the benefits to dementia care of adopting a palliative care approach, different models of care will be compared and the way care is organised will be discussed. I will consider societal responses to palliative care for groups of people with life limiting conditions and consider literature specific to care homes and palliative dementia care delivered within these particular settings.

### **2.3.2 In the literature, what is meant when dementia care is linked to palliative care?**

It is a concerning, but inevitable situation when the understanding of palliative care is unclear that this consequently impacts on the understanding of palliative care for people with a dementia (PWAD). Hertogh (2005) provides an example of this from a Dutch perspective. I intend to discuss statements he made in some detail, not by way of criticism, but by using his writing to highlight, what I

believe, are common critical issues of understanding. He is not a significant writer in this field, the writings discussed are taken from a book review he conducted for the journal *Alzheimer Disease and Associated Disorders*. The book he reviewed was titled *Ethical Foundations of Palliative Care for Alzheimer Disease*. Hertogh is described as a medical doctor working for the institute for research in Extramural Medicine in Amsterdam. I think this is highly significant as his views emanate from a learned medical research perspective, from a country where the issue of euthanasia and palliative care have been debated. His views are also recent, published in 2005 and were included in a peer-reviewed journal specific to dementia care. They were therefore not considered too 'off the mark'; to be published and in my opinion represent some commonly held views about dementia and palliative care, which require considered debate.

Hertogh (2005) described the development of palliative care as, 'originating in the field of pain management for patients with terminal metastatic cancer, the model of palliative care has now also found application in the care for patients suffering from chronic diseases ' (p159). There are many assumptions within this statement, which serve to highlight the varying perceptions of palliative care and, as a result, consequent confusion about palliation of PWAD. As discussed in section 2.2 an important aspect of palliative care is about pain management and presently most specialist services predominantly deal with people who have advanced cancer. This however was not how it originated and misses the vital notion of care for the person as a whole, incorporating physical, psychosocial and spiritual elements (Saunders, 1998 Twycross, 1980). Palliative care is also not about the care of people with chronic diseases but those who have diseases that are life limiting (Scottish Partnership for Palliative Care, 2006). This is a clear distinction, diseases that are life limiting, such as dementia, will from the point of diagnosis, have a significant impact on the person's quality of life and will contribute to their death (Albinsson and Strang 2002, Birch and Draper 2008).

Hertogh's (2005) comments highlight another issue that is related to perceiving palliative care as a specific body of people / services, most probably specialist services such as hospices or consultants in palliative medicine. 'During recent years the palliative care movement has extended its domain.' (Hertogh, 2005, p159). In my Scottish experience this is also a common perception, palliative care is synonymous with Macmillan nurses, hospices and people at the very end of their lives (receiving end of life care). The palliative care approach and generalist palliative care, as discussed in section 2.2 appear to be unfamiliar definitions and models of care. Palliative care is seen as specific people, buildings or only for one group of recipients, namely those dying of cancer. This raises questions of inequitable service provision for people who have life limiting conditions such as PWAD.

There is also a suggestion of cynicism in Hertogh's (2005) comment, 'the palliative care movement has extended its domain'. There is an implication of dominance on the part of the palliative care movement aiming to take over the care of people with conditions other than cancer. Throughout the work of this research, particularly whilst conducting the needs assessment, I have encountered these views. First in the difficulty of trying to link dementia and palliative care: is your research to do with people with dementia who have cancer as well? Is it about people with dementia who are close to death, at the terminal stage? I have also been aware of services that have voiced suspicion regarding palliative care services taking over roles traditionally held by other professionals for example community psychiatric nurses, in this context those providing mental health services. Hertogh (2005) in one introductory paragraph for a book review, highlights many of the fundamental issues that blur thinking around palliative care for PWAD and consequently, the author of this research would argue, this impacts on the experience of care.

In a literature review by Birch and Draper (2008) exploring the challenges of delivering effective palliative care to older people with a dementia, the focus of the paper was entirely about end of life care. This research reiterates that palliative care is for anyone with a life limiting illness, not solely cancer, and for

those who are not imminently dying and may have a prognosis of months to years. Despite this acknowledgement of general palliative care issues, the literature review focused solely on end of life care for PWAD. This implies that end of life care is the only issue involved in palliative care for PWAD. Communication and understanding of a dementia diagnosis, understanding the person's wishes and preferred care, carer support, legal issues and symptom management over months and years are all examples of important palliative care issues for PWAD which are not restricted to end of life care and as such require further research and practice development, (Bartlett 2000, Woodrow 1998, Morrison and Sui 2000, Kovach et al 2002, Scottish Executive 2005a). Small et al (2007) also reinforce the concept that various aspects of end of life care are necessary from the point of diagnosis and not only when a PWAD is in the final stages of dying.

Sachs et al (2004) in their paper about the barriers to excellent end of life care for patients with dementia in America, discuss whether dementia is identified as a terminal illness. A further dilemma regarding terminology arises here, what does terminal mean in this context? Within the United Kingdom, it has been defined as end of life care given during the final stage of an illness (Scottish Partnership for Palliative Care, 2006). The phrase terminal, within this American context, appears to mean life limiting or palliative, a much broader definition. Within Scotland the term progressive life limiting condition would be used in this scenario and dementia has been specifically identified as a progressive life limiting condition within recent publications (Scottish Partnership for Palliative Care, 2006). Sachs et al (2004) argue that American doctors specialising in dementia care consider it to be a terminal illness, however family members and other professionals do not view it as a disease that you would die from. It is evident that this scenario could potentially block the adoption of a palliative care approach or the utilisation of palliative care services, again potentially impacting on the PWAD experience of care and their quality of life.

Albinsson and Strang (2002) highlight that the long period of time between a diagnosis of dementia and death can reinforce perceptions that dementia care is not appropriate in terms of palliative care. Providers of palliative care services can be cautious about when and how to engage with PWAD and those with other non-malignant, life threatening diseases due to the unpredictability of the disease trajectory, particularly the provision of end of life care (Stewart and McMurray, 2002). Murray et al (2005) identified three trajectories for people with life limiting, chronic diseases. The authors classified them as relating to a cancer journey a respiratory / heart failure journey and a dementia journey. The cancer journey had a clear terminal phase, the respiratory / heart failure journey was gradual but had ups and downs showing both deterioration and recovery and more unexpected deaths, the dementia journey had a prolonged and gradual decline. From this evidence it could be argued that those service providers experienced in the provision of palliative care for people with cancer could feel unskilled and concerned about the impact on their services of working with people who have illnesses with markedly different and unpredictable disease trajectories. This potentially reinforces barriers that exclude PWAD from palliative care services.

Sachs' et al (2004) paper states that palliative medicine specialists in the United States argue that you do not need to be dying to receive measures of comfort, pragmatically however the authors acknowledged it to be easier to apply hospice and other palliative measures if a patient is considered to be terminally ill. Small (2007) reinforces this view, that presently end of life care is provided to those in the final stages of their illness. This is a key issue within this research, there are potential benefits of applying comfort measures aimed at enhancing quality of life (a palliative approach) for the PWAD and their carers from the point of diagnosis, not just at the last stage when death is imminent (Albinsson and Strang, 2002). This has particular resonance when consideration is given to the particularly overwhelming impact dementia has upon the person and their family. A key challenge is now evident, for connections to be made by professionals and the public between a palliative

care approach and dementia at the point of diagnosis onwards and not only when a PWAD is dying.

### **2.3.3 Promotion of a palliative care approach in dementia care: potential benefits**

Two United Kingdom dementia organisations, The Alzheimers Society and Alzheimers Scotland have both formally commented on and promoted a need for a palliative care approach for PWAD. 'The palliative care needs of PWAD have received little attention to date,' (Alzheimers Society, 2004). They focus on quality of life rather than length of life but limit this approach to people in the advanced stages of the disease.

Specific issues raised by The Alzheimers Society are artificial feeding and hydration in the terminal stages of the disease and managing pain and distress. They focus on partnership and decision-making between health professionals, care workers and family members. They specifically campaign for increased use and recognition of living wills / advance directives, involvement of carers in decision making and that palliative care should be provided in the person's existing setting. Similarly Alzheimer Scotland has focused on a need to improve palliative care for people with dementia. In 2007 Alzheimers Scotland held a national conference titled, 'Palliative Care and Dementia doing it better' the title speaks for itself. It is interesting to look at the content of the conference, which includes presentations on supporting family carers, pain assessment and management, communicating with the person who has dementia, legal issues such as power of attorney and advanced directives and the provision of spiritual care.

Research has identified that aggressive medical interventions for PWAD are of limited value but they also can cause distress and discomfort. Such interventions include, urinary catheterisation, taking blood samples, insertion of naso-gastric tubes, use of anti-biotics and medication aimed to sedate the person. Research conducted in this area has identified that PWAD experience these interventions unnecessarily and in some situations more frequently than

other patients, specifically those who have a cancer diagnosis, during the end of life phase, (Ahronheim et al 1996, Morrison and Sui, 2000, Volicer, 2001, Sampson et al 2006a, Sampson et al 2006b). Evers et al (2002) identified that potential reasons for this were an uncertainty about diagnosis and a consequent impact on medical interventions, an absence of advance directives that could steer and clarify medical care and a lack of medical staff training in regard to end of life decision making and care.

Is it feasible that a palliative care approach, incorporating physical, social, psychological and spiritual aspects, whilst caring for people as individuals, using good communication and respecting autonomy and dignity (Scottish Partnership for Palliative Care, 2006), could provide an overarching care and support system for PWAD and their carers? As an approach it is holistic and symbiotic with Kitwood's (1997) person centred approaches. Hughes et al, (2005) supports this argument, stating that the palliative care approach equates to person centred care in dementia. A potential advantage however of the palliative care approach, in comparison to Kitwood's (1997) person centred and personhood theories, is their applicability in practice. Both generalists and specialists in palliative care have developed assessment and intervention methods and systems of care, which provide practical application of this approach (Care Commission 2003, Ellershaw et al 2003, King et al 2005). An example is the essential requirement of a multidisciplinary team to address the holistic needs of patients and their families within Scottish hospices. The care commission's standards for specialist palliative care services (2003) specified the disciplines to be involved and their presence is now mandatory. This multidisciplinary working directly reflects the components of palliative care identified above, with each discipline providing a specific focus but contributing to the whole experience of care in response to the person's need. In comparison there has been criticism that Kitwood's theories, although very significant and core to the historical development of dementia care, have struggled to find application within practice settings due to a lack of clarity of definition (Killick and Allen, 2001).



### **2.3.4 Models of palliative dementia care**

It is helpful to clarify approaches to palliative care for PWAD in the United States and the United Kingdom. In the United Kingdom, as described in detail in section 3.2, very few PWAD are cared for within hospice settings or receive support from specialist palliative care services. The potential reasons for this are that priority is given to people who have cancer, those who have the most complex pain and symptom control problems and those who are imminently dying but in a setting, which is not able to meet their needs. A further potential reason is that healthcare professionals may not consider a palliative care referral, due to the fact that the main problem is not cancer. For PWAD it is likely that their care providers will include services from primary care, social care, mental health, dementia specific services and should they be available, carer support agencies. In summary the majority of services involved will be generic with some input from more specialist dementia services. This situation has arisen due to dementia care predominantly being the responsibility of elderly, mental health services and social care. It is only in the last ten to fifteen years' connections have been made between palliative care and dementia, in conjunction with other non-malignant, life limiting conditions. Within the United Kingdom however this has had little impact on specialist palliative care services other than an emerging research agenda identifying the needs of people with non-malignant life limiting conditions and how services respond to these needs (Scottish Partnership for Palliative Care 2006, Regnard et al 2006, McCarthy et al 1997, Albinsson and Strang 2002, Shega et al 2003, Evers et al 2002, Keene et al 2001).

In the United States there has been a similar historical development of palliative care alongside cancer care, but a recognition exists that PWAD are losing out, 'people with dementia often die with inadequate pain control, with feeding tubes in place and without the benefits of hospice care' (Sachs et al, 2004, p1057). The health insurance system, which operates in the United States of America, places restrictions on PWAD receiving hospice care. Criteria for health insurance plans stipulate that a person entering a hospice programme should have a prognosis of 6 months or less. Sachs et al (2004) point out that this sort

of decision-making around prognosis for PWAD is exceptionally difficult as the duration of the disease is more variable than for people with advanced cancer. It would appear that one of the main issues blocking hospice care for PWAD in the United States of America are the criteria arising from insurance health plans. It is evident that the provision of palliative care for PWAD is inequitable.

An American model of palliative care, worthy of discussion, is the PEACE programme, Palliative Excellence in Alzheimer Care Efforts (Shega et al, 2003). The authors identified that PWAD in America are infrequently referred to hospice and that barriers exist to extending the service to this population but also early referral to palliative care would be beneficial. The programme focuses on end of life care but also aims to integrate palliative care into the primary care of PWAD throughout the course of the illness. The programme achieves this by focusing on primary care geriatric doctors. These doctors follow a disease management model, which incorporates advance planning, patient centred care, family support and an ongoing focus on palliative care. Shega et al (2003) achieve this predominantly by using researchers to conduct regular interviews with clients and their carers. These interviews are reviewed by Clinical Nurse Specialists who initiate interventions and review progress with doctors. The research interviews involve a surprisingly large number of questionnaires and tools including depression scales, and a mini mental state examination. In total eleven specific scales and other questions were completed, interestingly but not surprisingly the interview schedule was shortened as people experienced fatigue when participating in the interview. This programme aimed to ensure that PWAD were enrolled in a hospice programme for end of life care, this was a positive outcome. In essence the usefulness of this care model is the agreed and purposeful adoption of a palliative care approach by a defined group of professionals. Sadly this model of good practice is not widely evident and appears to have been developed as a result of local initiative.

There are many similarities to this model and the Gold Standards Framework (King et al, 2005) described in section 3.2. Similarities such as community care

practitioners working with a system to identify and provide ongoing multidisciplinary assessment and interventions for people with a life limiting condition. A significant difference however would be that in the United Kingdom, the option of hospice care for PWAD would be unachievable unless hospices radically changed their admission criteria and there was an increase in these services to cope with increased numbers of clients who have both malignant and non-malignant disease. The equivalent of hospice for PWAD in the UK would be in-patient care within a care home or an NHS hospital psychiatric ward. Literature relating to this will be reviewed later in this section.

It is interesting to debate how in British society, differing values are placed on the care given to groups of people with specific diseases. We have already discussed the services available to people with dementia compared to those who have cancer. These people and their families have been identified as having very similar needs but receive very different levels of service provision (McCarthy et al, 1997). In a similar way children, who have life limiting conditions, have access to a range of flexible services, which meet their needs and those of their carers. Rachel House in Scotland serves as a specific example, respite care is offered exclusively to children with life limiting conditions.

The significant issue about Rachel House, in the context of this literature review about models of palliative dementia care, is that its service would be ideally placed to provide individualised, proactive care for PWAD and their carers, but such a service does not exist, certainly within Scotland. Children at Rachel House receive high levels of attention and care from staff who work along side the family, respite is a priority for families and planned proactively and provided flexibly from a holistic standpoint. Children there are active, participating in games, cooking, art therapy, music therapy, snoezelen sessions and outings. Provision of physical care is only one aspect. Clearly the positive environment, staffing levels, multidisciplinary working and the ethos of the service provides a rich quality of palliative care experience, for those children and their families who experience it, this is indeed to be applauded. It serves to highlight however

the distinct contrast in palliative care services available, in this instance, for children and for PWAD.

Downs et al (2006) wrote a theoretical paper about models of dementia care and how these linked to end of life care. The authors identified four models of dementia care:

- Seeing dementia as a neuro-psychiatric condition,
- As a neurological condition,
- As normal ageing
- As person centred care.

The authors argue that dependent upon the perception / conceptualisation of the service provider and the model adopted by them, this will have an impact upon the assessments and interventions undertaken and the care experience. For example seeing a PWAD as someone with a neuro-psychiatric condition can result in the focus of care being on medication to treat cognitive and behavioural problems. The authors also highlight that this approach can negate and minimise the impact of the problems on the family of the PWAD. Downs et al (2006) support and encourage practitioners to consider person centred and palliative care approaches as a way of conceptualising dementia care and positively impacting upon care delivery where the PWAD is at the centre. It is worthy of note that this paper also focuses on palliative care for PWAD as relating to end of life care. I would argue that a person centred / palliative care approach could positively impact on a PWAD from the onset of problems and not only restricted to end of life care.

The experiences of this study identified that meeting only the basic physical care needs of 30 women with severe dementia in a community hospital was at times unachievable, any activities or stimulation they receive is regarded by staff as a bonus. This uncomfortable scenario raises the question of why we treat different groups of people, who have palliative care need, so differently. Is it disquiet caused by 'the mad and the elderly' and wanting to hide them away, a throw back to care provided by asylums? Are there too many PWAD to even

consider the economics of providing the type of quality of service provided to children at Rachel House? Should we silence these ambitious thoughts and content ourselves with current service provision and focus on meeting only the physical needs of PWAD? In essence comparing these two models of care highlights the ethical and pragmatic struggle that ensues when beginning to address the palliative care of PWAD and their carers. These issues are bigger than the responsibilities of health boards and local government, they are instilled within our general society and the attitudes we have to older people and furthermore to older people who have a dementia. Hughes et al (2005, p57) stated, 'In its latest report on palliative care, the health committee of the house of commons recorded the Department of Health's admission that the lack of palliative care for patients without cancer was the greatest inequity of all.'

It is interesting to compare organisational models of care from my own experience within cancer palliative care with the organisation of dementia care. My previous experience of cancer care has enabled an awareness of the successes of managed clinical networks for cancer. Scotland has three geographical managed clinical cancer care networks, whose role it is to improve the care and services provided to people with cancer. The South East Scotland Cancer network (SCAN) is highly organised in structure, has financial support from the Scottish Government with full time managers, staff and lead clinicians. They influence care directly by gathering and analysing statistics, which report on performance. They provide a cohesive approach as they bring together key individuals from relevant services and disciplines and make decisions about the way care is delivered, for example managing waiting times for cancer treatment in line with Scottish Government targets as determined in Delivering for Health (Scottish Executive Health Department, 2005a). One of their key strengths is the strong connection they have with practitioners, NHS Boards and strategically with the Scottish Government Health Department. Their impact on service delivery is impressive (SCAN, 2006). It is clear to see how these Scottish networks can influence, co-ordinate and improve care for people who have cancer. To date such organised networks do not exist within

dementia care in Scotland and it could be argued that as a consequence service co-ordination is poorer as a result.

Within the local context of this research, West Lothian, I tried to determine which management forum would discuss dementia care issues, it was evident that no specific meeting or committee existed. Dementia issues were addressed within an older people's forum but were discussed infrequently and with little impact on services. The above scenarios clarify why developments in dementia care are difficult. There are potentially many reasons for this, it could be argued that dementia care does not follow a strict medical model and a clinical network approach, such as the SCAN network described above, may be inappropriate. A key issue is that dementia care requires a strong working relationship between health and social care services, therefore immediately there are challenges as you have two organisations that are separately financed and managed but are required to work together. During this period of study, West Lothian changed their arrangements for managing health and social care and a joint Community Health and Care Partnership was established. This initiative will be discussed later in this research.

There are a number of models or approaches to care, which have arisen from a specific dementia care perspective, which could also be described as following a palliative care approach. Alzheimer Scotland has a service for younger people with dementia. The model of care involves a link worker being assigned to a PWAD and their carer from the point of diagnosis onwards. The aim is to provide a continuous link and point of contact for both the affected person and their family. The link worker has a lot of involvement at the beginning in terms of providing information and support, and specifically ensuring legal and financial issues are considered. The aim of more intensive involvement initially is also to form a relationship of trust and support which can be useful over time. The link worker would meet the PWAD and family less frequently if there were no specific problems but be available and increase input as necessary dependant upon individual circumstances. A key role of the link worker is the knowledge of available services and the ability to suggest referrals at

appropriate times. It is evident that this model provides continuity and that an understanding of the person can be transferred from one service to another as needed and minimises the difficulties of the person being moved from one service to another in a disconnected way. Very positively this service addresses an individual, ongoing, person centred and flexible service and clearly addresses many aspects of what could be described as following a palliative care approach. Currently this service is limited to younger people, although some areas of Scotland adopt this approach for all people who have a dementia. The benefits of this approach are evident but pragmatically there would be challenges in setting up and resourcing this dementia specific service where it doesn't currently exist.

Other dementia specific approaches to care undergoing research focus on quality of life, communication and social aspects of a palliative care approach (Ward et al, 2005). The good sunset project: quality of life in advanced dementia (Killick and Allan, 2005) aims to develop ways of communicating with people who have advanced dementia and who are near to death, with a view to understanding their experiences and needs and thereby improving their quality of life. This was a multiple activity project working with staff, managers and PWAD. The focus of the work was how to connect and communicate with individuals who have advanced dementia. The data was subjective and the work acknowledged as a pilot study, and in terms of research methods could easily be criticised, as much of the interpretations are subjective and emanate from two experienced individuals enthused about this particular area of care. It does however open up issues in an area of care that has previously been neglected in terms of study. The authors used coma work principles as described by Mindell (1999) to connect with a small group of individuals. The activities involve a focus on breathing, touch, close observation and mirroring of the person's behaviour. Sessions were taped on video and analysed. The analysis focused on the responses of each individual. They experienced communication with people, expression of emotion and music and touch appeared to be important during the interactions.

This area of care is one that causes families distress as they struggle to cope with their encounters with their family member in the very advanced stages of dementia. This research is also relevant to staff as they support families in these situations (McGarry Logue, 2003). These particular aspects of communication could be described as specialist practice in terms of dementia care and may potentially offer insights to other palliative care practitioners. It could be argued that the exploration of alternative ways of communication and making person centred connections with PWAD, may be an aspect of care that could influence palliative care practitioners working with other life limiting conditions.

### **2.3.5 Palliative care in care homes for people with a dementia**

Palliative care within care homes: Evans (2002) states that the majority of residents within nursing homes have some degree of dementia and therefore this is an important care setting to investigate in terms of palliative dementia care. In conjunction with this the numbers of older people dying in care homes is also increasing. Evans (2002) states that in the United States of America, 20% of all deaths occur in care homes, and the fact that half of care home residents die within their first year, highlights a need to provide effective palliative care. Sidell et al (1997) highlighted that 15% of residents in nursing homes die of a terminal disease but 42% die after prolonged periods of deterioration. The Australia Institute of Health and Well-being (2005) identified that 19% of residents of care homes in Australia will die within twelve months of admission. These are significant statistics, which highlight the increasing role care homes have in delivering palliative care.

Katz and Peace (2003) are acknowledged for highlighting the issue of end of life care within the care home setting and have undertaken research investigating how death and dying is managed within care homes and the role of training. Katz (2005) specifically highlighted an urgent need for more research to be undertaken in regard to the palliative care needs of PWAD in care homes.



Phillips et al (2006, p417) describes Australian residential care facilities as having changed function from centres of rehabilitation to 'de facto hospices' and are now the last frontier for palliative care. Their research, analysed how care homes adopted a palliative care approach. Their concern arises from the fact that the Australian government is promoting palliative care policies within such facilities but how does this work in practice. Their qualitative enquiry concluded that this care sector needs additional education and support in regard to symptom control, language and access to specialist services and resources. Staff were committed to providing good quality palliative care but felt they were battling and striving against the odds. Specifically they felt a strong role in advocacy but experienced challenges in communicating with other healthcare providers.

Hockley (2002) identified how specialists in palliative care have focused attention on the care home sector in the UK, and aimed to enhance end of life care through the implementation of quality initiatives. She has also identified a different knowledge requirement for staff in care homes, compared to those within specialist services, about delivering quality end of life care. Froggatt and Hoult (2002) explored how Clinical Nurse Specialists in palliative care engaged with care home staff in the development of their palliative care practice. They found that these nurses were involved, in a reactive way, with specific clients regarding the provision of advice. The specialist nurses did perceive areas of need regarding palliative care practice and education within care homes, but were only able to give limited support in regard to this. Katz et al (1999) identified that the term palliative was not a familiar one to care home staff, however they were keen to provide care, which followed a palliative care approach. The main constraints experienced by the care homes were the palliative care support given by General Practitioners and specialist palliative care staff but also staffing levels and relevant training impacted on the care staff aspired to provide. A concern identified by Sidell and Komaromy (2003) regarding poor outcomes for older people dying in care homes, was the

substantial numbers of dying residents transferred to hospital in their last days of life. These decisions to transfer the dying relative did not always involve consultation with the resident or family.

Froggatt and Payne (2006) conducted a postal survey of 115 care home managers in England to investigate their views about the provision of end of life care for older people in care homes. They found that managers focused on the period close to the resident's death or the death event itself, there was little consideration of broader issues of palliative care such as dealing with loss, for example the loss of their own home, nearby neighbours. The authors argue that it would be helpful if end of life care could be reframed to give consideration to all the care provided. The authors do acknowledge that the terminology of end of life care is confusing. From a simplistic standpoint, referring to a form of care as: end of life, would do little to encourage people to think more broadly, for example what would end of life care have to do with the admission of a new resident? The authors purport that it is care home managers that determine the culture of care and that they are vital to ensuring care practices are developed, hence their involvement in the postal survey for this research. The author of this research would argue from experiences of practice development within care homes, that groups of staff such as nursing assistants can, in reality, be the instigators and change agents in respect of the culture of care, not necessarily the manager.

Within a Scottish context the joint publication by the Scottish Executive and the Scottish Partnership for Palliative Care (2006) Making good care better: National practice statements for general palliative care in adult care homes in Scotland, provides an excellent research based framework to develop care within care home settings, however as described previously, to date no support in terms of finance or practice development activity has been provided to facilitate this. In respect of care homes this must be a frustrating position, with external organisations identifying what palliative care practice should look like in care homes but no support to achieve this.

It is clear from the evidence presented, that this is a priority area in terms of research and practice regarding palliative care of people with a dementia within the care home setting.

### **2.3.6 Palliative care for people with a dementia: key areas of research**

As well as research into care for PWAD in care homes, discussed above, there are some key research issues being taken forward that are concerned with palliative care for PWAD. These are:

- The assessment and management of pain for PWAD
- How to support family carers of PWAD.

As described earlier, through the progress of this action research, these two key areas also become the focus of activity and development with services participating in the research. In light of this, literature reviews relating to both of these subjects are included in the beginning of chapters six and seven.

### **2.3.7 Key messages from literature review on development and current issues in the palliative care of people who have a dementia**

- Dementia type illnesses are not always considered to be palliative by professionals that provide care or by those in society. This can block the adoption of a palliative care approach and / or access to appropriate services.
- A lack of clarity on the part of service providers, about delivering a palliative care approach and the provision of general and specialist palliative care can impact on the care experience of PWAD.
- The inadequate adoption of a palliative care approach for PWAD, is negatively impacting on the provision of care in accordance with individual preferences and the prevention of unnecessary and unwelcome interventions such as the insertion of feeding tubes and giving of intravenous hydration.

- There are inequitable variations in the palliative care provision for groups of people who have different illnesses, for example children with life limiting conditions and people with cancer compared to PWAD.
- Examples of good palliative care practice for PWAD are evident in literature however they are inconsistent and dependent on local initiatives.
- Palliative care provided within care homes has been highlighted as an important area for development as increasing numbers of PWAD are cared for within these settings.
- Although aspirational standards of palliative care within care homes have been identified and recorded, there has been a lack of practice development activity and resource to enable staff to achieve these.

## **Chapter 3**

### **Research Methodology and Methods**

#### **3.1 Introduction to chapter**

This chapter commences with a statement of the research aims and a section justifying the adoption of an action research (AR) approach for this study. Following this a series of key components of AR will be presented from literature and debated in the context of this study. The following key components of AR are included: AR theories, methodological approach and development, participation and democracy, first and second person enquiry, reflexivity, action research cycles, developing a baseline understanding, validity and reliability, ethical considerations of conducting research with PWAD and their carers. Continuing through these discussions, justification for adopting a participatory action research approach for this study will be presented. The chapter concludes with a description and justification of the specific methods used in this research and their relationship with first and second person enquiry.

Action research is a complex process with many issues to consider. In respect of this, a degree of detail and argument is presented within this chapter in order to provide explanation and justification for the decisions and actions taken during this period of study.

#### **3.2 Research aims**

In preparation for discussion of the research methodology it is worth restating the overall aims of the research:

1. Identify the palliative care needs of people with dementia and their carers in West Lothian.
2. Describe and analyse two dementia care services in West Lothian as they develop an aspect of their palliative dementia care practice: specifically the assessment and management of pain and distress for

PWAD (Almond Ward) and supporting carers of PWAD (Meadow Day Centre).

3. Analyse the learning that occurs between dementia care practitioners and a facilitator experienced in palliative care during this action research.
4. In relation to the assessment and management of pain and distress for PWAD and supporting carers of PWAD, determine potential future implications for practice development and service delivery.

### **3.3 Justification for adopting an action research approach in this study**

AR was specifically chosen as the research approach for this study for a number of reasons. Primarily, there was a necessity not only to describe and understand the palliative care needs of PWAD and their carers, but also to work alongside service providers to change, develop and evaluate care practices, directly in relation to the needs identified but also within the local context of their service. Through the experiences of developing their practice, it was intended that new knowledge would be identified. This new knowledge for example, could take the form of developing a new understanding of the experiences of PWAD, their carers and service providers, the practice implications of incorporating evidence into clinical practice and developing, contesting or confirming existing theories related to caring for PWAD and their families. Hockley and Froggatt (2006) highlight the importance of an action research approach when new knowledge is required directly from a practice setting, and particularly when this involves implementing a change. Within an action research approach, new knowledge could arise not only from the outcomes of the research but also in the evaluation and learning that occurs as a result of the research processes themselves. This action research approach was also an integral part of the parent project.

A significant aspect of AR is that it takes place in real time, therefore practice development occurs amidst the ordinary experiences and demands placed upon any service at any given time. In this way any learning and development that takes place is real but has to be understood within a specific context and time. The relevance of this is that other service providers may consider the

implications of the research in regard to their own service, considering similarities and comparisons and making judgements about what may be possible for them within their own context. In terms of care for PWAD and their carers, the literature review for this thesis highlighted a need to understand how to practically develop and enhance care practices in light of, for example, theories of personhood with the ultimate aim of improving the care experience.

Specifically the assessment and management of pain and distress for PWAD, and supporting carers of PWAD, were identified as priorities within the initial needs assessment process. The action phase, which followed the needs assessment, specifically addressed these needs whilst simultaneously meeting the individual practice development aims of participating services.

A key element of this action research approach is conducting research with people rather than on them, with the deliberate aim of actively engaging service users, changing and evaluating practice developments that are regarded as relevant to participating services. An overt aim would be that participants shape the research subject and the process of investigation.

By way of providing a methodological research comparison, a quantitative study would have required a much sharper subject focus, predetermined by the researcher, with a specific aim of investigating a hypothesis or null hypothesis. The researcher would determine the focus of this type of study in advance, and those taking part would be regarded as subjects rather than participants. Following a deductive approach such as this would have an overall aim of proving or disproving a theory with the potential end point in the future of achieving some benefit to treatment or care. There would be no deliberate intention that subjects would benefit from taking part in the research process itself or that practice would directly be enhanced through this process. Important considerations within a quantitative study would include sampling methods and size, issues of bias and objectivity, data capture and measurement that enables quantification and correlation of predetermined variables. In contrast to this quantitative approach, this study has a direct

intention to impact upon practice through participation and involvement with key stakeholders: patients, relatives and staff.

It is possible that future studies could adopt a quantitative methodology in terms of studying the management of distress for PWAD. The challenge would be determining measurement scales for distress and contentment when this is regarded as a highly individual phenomenon, and determined by behaviours unique to each person. A particular challenge here is the inability to self report. In terms of the assessment tool used in this study, the DisDAT (Regnaurd et al, 2006), further development work would be required to enable statistical analysis of these individual behaviours. There would be a need to compare behaviours pre and post an intervention such as relaxation, a control group would also be necessary. It is arguable that further descriptive qualitative evidence regarding this form of assessment would be necessary to understand more fully and in a more definitive way the nature of this assessment and its use in practice areas before quantitative studies could be undertaken.

In terms of research into carer interventions and support, quantitative work has already been undertaken. As discussed in the literature review chapter, Markowitz et al (2003) investigated health related quality of life for caregivers of people with Alzheimers disease in the United States of America. In a large study (n= 3019) using validated measures (SF-12 short form and a variety of scales measuring disease severity, functioning and utilisation of services) they determined that providing care had an impact on health related quality of life for caregivers. Specifically their sample of caregivers showed that disruptive behaviour and depressive symptoms of people with Alzheimers disease and the volume of time spent caring had a deleterious effect on caregivers. Factors which enhanced caregivers health related quality of life, were increased social support and a reduction in hours of caring. A key difference with this research and the potential research of contentment and distress for PWAD is the ability of participants to self report and therefore have measurable values identified from what is said enabling statistical comparison and correlation.



A quantitative study by design would not address the needs of individual participating services and therefore fail to foster involvement, democracy, ownership and participation, key objectives of this research. This research is rooted in the reality of practice and the experiences of developing care in a real world setting. The experiences and learning gleaned from services developing their palliative dementia care practice, as part of this research, would provide evidence and lessons learnt for other services aiming to achieve similar developments. This is not to infer that the research is directly transferable as all services and contexts are unique. Those reviewing publications associated with this research and its findings, would require to determine which elements of the learning identified within this study would be relevant or applicable to their practice setting, staff and clients.

It could have been possible to adopt a different qualitative approach to this research such as ethnography. The purpose of ethnography is, 'to understand human behaviour in the cultural and social context in which it takes place,' (Parahoo, 1997, p150). Data collection would generally include observation, interviews and reflective field notes, a key principle of ethnography would be that, 'the researcher looks at phenomena through the lenses of respondents' (Parahoo, 1997, p151). The overall purpose is the provision of a rich description of a culture or context such as a day centre or hospital ward. To a degree this study about palliative care for PWAD has an ethnographic element to the investigation, however the overall purpose is different as this study aims to directly change practice as well as develop an understanding of the context and culture. Action researchers would argue that an understanding of context enables a realistic approach to the change process and the opportunity to identify what issue participants would like to change.

There was a strong desire that this research would adopt an inclusive and collaborative approach, specifically including PWAD, their carers and the staff (at all levels) and volunteers from participating services. The notion of inclusion and collaboration would be continuous, not only in terms of providing data at the commencement of the research but also being actively engaged in analysis

and practice development processes, essentially at each stage of the action cycle. This is in keeping with an aim of democratic processes in AR (Meyer 2000, Reason 1988, Livesey and Challender 2002) described later in this chapter. At the outset, the specific activities of the research were unknown, but were reliant upon the identification of need and the direction of participating services. An AR approach acknowledges this democratic way of working, other research approaches would usually commence with a more defined objective.

Empowering PWAD, their carers and service providers was a further aim of this research; an AR approach aims to facilitate this. A number of activities were undertaken to hear the voices of PWAD, even those with severe dementia. Activities sought to support family carers aimed to empower them in their role as carers, and practice developments within services were undertaken in ways that would enable providers to develop their skills and take responsibility for these interventions, aspiring for service developments that are sustained.

### **3.4 Action research (AR): methodological approach and development**

I intend to briefly describe the historical context of AR and its methodological approach to research. Kurt Lewin is generally regarded as the founder of action research. He was a Prussian psychologist who held left wing political views and it is argued that from these political beliefs, his approach to research emerged. He used the terms rational social management and action research interchangeably; 'a form of research which could marry the experimental approach of social science with social action in response to major social problems of the day', (Kemmis, 1982, p13). Hart and Bond (1995) described the process of steps Lewin identified as AR. The first step involved examining an idea and the potential that an objective could be achieved. An overall plan was developed regarding how to achieve the objective, and a first action step was agreed. The action step was completed and evaluated and the next step planned. With each step, the following processes were undertaken; planning, executing, reconnaissance or fact finding in regard to the next step. At each step there was the potential to reconsider the overall plan and agree any

modifications. From this early description of AR or rational social management a continuing spiral approach to the process can be identified.

Meyer (1993) argues that the modern elements of action research continue to be based on Lewin's four-step framework of planning, acting, observing and reflecting. Evaluation is identified as a key activity, determining whether a change has occurred as a result of actions taken.

Two modern day educators, Carr and Kemmis, are exponents of action research and have published widely in this area. They identified two areas of modern action research, which are now in contention with Lewin's original ideas. First that group decision-making is fundamental throughout all stages of AR and secondly that democratic working underpins the whole process, and is not merely a potential or aspirational way of working as described by Lewin (Carr and Kemmis, 1986). It could be argued however, that Carr and Kemmis' more recent views may not directly be in contention with Lewin, rather that they represent a progression or development of his original ideas, remaining founded on an ideology of social justice and working to address social problems. Their views appear more defined and potentially influenced by their professional practice in education. Within this study effort and time was focused on working with key professionals, developing positive relationships and working in an inclusive manner where contributions were valued and acted upon. Key professionals had a responsibility to cascade information and engage other members of the team. In this way group decision making and democracy were put into practice.

Karim (2001) identified that AR cannot be categorised as either qualitative or quantitative, and Webb (1990) argued that the rise in popularity of AR is a result of the limitations of these research approaches. These limitations are particularly noticeable when investigating change and practices within social organisations and structures. Objective research, focused on deduction and causal effect, namely positivist approaches are being increasingly criticised within these contexts (Meyer, 1993). Concerns specific to qualitative

approaches such as ethnography are also presented in literature, due to their inability to address the unequal power relationship between researcher and subject, where the aim is to accurately portray experiences and situations (Meyer, 1993).

In stating these positive arguments about AR it is necessary to acknowledge that AR can be viewed less positively with researchers whose practice is solidly grounded in both qualitative and quantitative paradigms. For quantitative researchers the quasi-experimental nature of AR and its apparent strong links with practice development approaches can align AR with audit or a less robust form of enquiry where causal effect cannot be determined. The AR approach can be classified as following a service improvement methodology rather than rigorously conducted research. In respect of qualitative researchers, a similar argument focussed on the depth and rigour of data analysis conducted in action research can be identified. In comparison to a qualitative approach such as discourse analysis for example, the analysis conducted in AR can appear less rigorous and detailed.

Action research is identified with critical theory and feminist approaches in that the overall aim is social change through empowerment of participants, usually participants for whom there is some discernable imbalance of power Karim (2001). In terms of power imbalance, this is particularly the case within this research in regard to people who have a dementia and their carers, an acutely vulnerable group of people in their own right and for their carers, who are deemed vulnerable and in need by association. These power imbalances also impact on nurses and social care staff, the professional groups that are the focus of this research. Nurses and social care staff have historically been of lower status and power than doctors, however each group are required to work in an interrelated way, both within and across care settings and most specifically in regard to the subject of this research, palliative care for people with a dementia. Providing support for PWAD and their carers during their dementia journey, very particularly involves multiple services and joint working from both health and social care. This study is focused on empowering staff

from participating services to enhance an aspect of their practice and service but also to provide carer support interventions that empower carers in their caring role.

A number of authors highlight the importance of the role of the researcher within AR (Hope 1998, Meyer 2000, Wadsworth 1998). AR is conducted through this person therefore it is primarily an interpersonal activity, less focused on methodological issues (Meyer, 1993). To a large extent, the quality of the research is directly dependent on the skills, knowledge and experience of the person concerned. AR literature identifies two categories of action researcher, the insider and the outsider (Coghlan and Casey, 2001). Logically the insider is someone who already works within the organisation, who takes the opportunity to address a recognised problem by using an AR approach. The outsider, being one who is external to the setting, but has something to offer the service by undertaking AR. Commonly within nursing, this can be someone within education who may have clinical links with the area. They may provide both the knowledge and experience of relevant clinical issues as well as AR. Coghlan and Casey (2001) argue that the majority of AR literature focuses on the outsider model. This makes sense, in that many 'outsiders' will be undertaking AR as part of a higher degree, as is the case with this research, and will want to have experiences and findings published. There could potentially be less confidence, focus, time and energy, on the part of insider action researchers, to publish their work and findings.

It could be argued that defining an action researcher as either an insider or an outsider is a somewhat artificial classification. During this research I could have been deemed an outsider, as I was unfamiliar with both of these practice settings prior to commencing the research. I did not know the staff, I was unfamiliar with the services, how they worked and their aims. I was particularly unfamiliar with the day centre as it was part of a social care service. On a broader basis I had not worked within the mental health department of this hospital before, so there was a different group of managers and ethos to become orientated to. Although I had trained and worked as a mental health

nurse, I actually had relatively little experience of working with PWAD, apart from the experiences and information gathered whilst conducting the dementia palliative care needs assessment (Chapter three).

It could be argued that I may equally be described as an insider in that I am a nurse and have worked in other mental health assessment wards in hospitals before, therefore have a broad, if not specific understanding of the aims, activities and ethos of this type of setting. It is also within usual practice for nurses to move between settings so this is also a professional norm. As a nurse of more than 20 years I am embedded in the culture of this profession therefore could strongly be identified as an insider in terms of professional status, if not specifically to the immediate environments of the two services participating in the research. Although my working experience has been within health and the voluntary sector (palliative care) it could still be argued that I was an insider within the social day care setting as in the past I have been the manager of a day care service if not specifically a social care day service. As a result I had an awareness of many of the issues faced by the day care service based on previous knowledge and experience. The day care service I managed was also part of a charity therefore many links existed between my past role and current involvement with the Day Centre as it was also a registered charity.

I presented myself to patients, relatives and staff as someone who was an experienced nurse with a background in palliative care, particularly cancer palliative care and that I also had experience of conducting research working with staff to develop their care practices. I actively highlighted that this research aimed to focus on learning ways of developing dementia care in the same way cancer palliative care has developed through hospice care and Macmillan Nurses. Discussions with patients, relatives and staff involved talking about dementia care in terms of palliative care. For many participants this was a new and different perspective and required some consideration and discussion. Specific time was taken to meet with people from participating services to gain their consent and ensure an opportunity for these discussions to be held.

A further element of the insider / outsider debate relates to time and the changing relationships that occur between researcher and participants in AR. I would argue that this also impacts on whether someone is considered an insider or outsider. I worked with the participating services for two years and three months and the relationships changed over this time. To some extent, due to the length of time of the research, I became part of the furniture, familiar with the cultures, ways of working and the personalities of staff. There was a definite sense of moving to a more insider form of perspective. To conclude this debate regarding whether I acted as an insider or an outsider as part of this action research study, I would determine that these are artificial boundaries and a sense of transparency is required. At different levels I could have been deemed an insider or an outsider, levels such as professional background, organisational context and previous related experience. An important factor in this argument however was the ability of the researcher to carefully observe care practices with a critical eye and ensure the facilitation of feedback and discussion without participants feeling a sense of judgement or undue sensitivity. These 'working alongside people skills,' were essential in terms of engagement, participation and democratic working. I would argue that previous experiences and knowledge of practice development approaches enabled the positive fostering of these relationships.

### **3.5 Theories about action research**

This section will present and discuss theories related to the conduct of action research. Theories presented include a typology of action research, action science and the theory of action. Application of these theories into action research processes will be discussed.

Hart and Bonds (1995) typology of action research, provides a useful overview and theory of what action research is about and what it would aspire to achieve. The list of seven criteria include:

1. AR is educative
2. Deals with individuals as members of social groups

3. Is problem focused, context specific and future orientated
4. Involves a change intervention
5. Aims at improvement and involvement
6. Involves a cyclic process in which research, action and evaluation are interlinked
7. Is founded on a research relationship in which those involved are participants in the change process (Hart and Bond, 1995, p.37)

On examination of the above criteria however, there is one element that could reasonably be described as missing. That is the importance of reflective processes within criteria number six, the cycle of research, action and evaluation. Potentially reflection could be assumed to be part of evaluation, however some authors would argue the importance of specifically highlighting reflective processes as an essential element to AR (Rolfe et al 1995, Badger 2000, Hart and Bond 1995, Meyer 1993).

Hart and Bond (1995) developed their action research typology in order to highlight the different approaches to action research. Hart and Bond (1995) determined a need for a typology as they were concerned about the lack of precision in terms used related to action research. Adopting a more cynical standpoint, they describe action research as a label, which can be used to benefit researchers, however this labelling has served to confuse and blur the understanding and usefulness of action research. They argue that research, which utilises feedback and collaboration, has been termed action research, despite no other features of action research being present. From a different perspective action programmes conducted by a researcher have also adopted the term to enhance academic credibility and standing. The authors describe four types of action research; experimental, organisational, professionalising and empowering. The experimental form of action research is at one end of a continuum, which purports a consensus model of society, where rational social management dominates. The other end of the continuum represents a conflict model of society involving structural change. Dependent upon the aims and



nature of a particular action research, Hart and Bond (1995) argue that it will fall into one of these four categories.

Dependant on the type of action research, (experimental, organisational, professionalising and empowering), the purpose of the data collected during the pre-understanding phase will have different functions, in experimental action research for example, data collection in this case aims to prove or deduct, that the planned action or intervention had a causal effect and achieved a defined outcome. At the other end of the continuum in 'empowering action research', initial data collection would focus on description, particularly the context, the players and understanding different definitions and perspectives of the practice problem. As empowering action research focuses on users and empowering oppressed groups, initial data would need to attempt to capture these phenomena and concentrate on relationships and power balances.

This research about the palliative care of people with dementia demonstrates a blurring of Hart and Bond's typology of action research. This study leans more towards a professionalising type of action research. There will be a focus on service providers and practitioners and it is they who will determine the area of change on behalf of users. In terms of the change intervention the outcome would relate to professional, evidence based practice, however to achieve this aim, there requires exploration and understanding of the problems at hand, which in this aspect of Hart and Bonds typology, would be more associated with an empowerment model of action research. From the perspectives of this research described above, it can be demonstrated that the boundaries identified by Hart and Bonds' 1995 typology, can in fact be blurred and within the realities of action research practice could be described as artificial, this criticism is also echoed in literature (Meyer 2000, Badger 2000).

Further theories exist in relation to a notion of action science and action research. Friedman and Rogers, p252 (2008) argue that action science, 'is not a distinct method, but rather a set of value based conceptual and practical tools that can be integrated into and enhance many forms of action research'. Action

science has been described as a form of research that rejects positivist methodology but purports to explain phenomena, inform practice whilst remaining embedded in the principles of scientific enquiry. Friedman and Rogers (2008) identifies five key features of using an action science approach: creating communities of enquiry within communities of practice, building individual and collective theories of action, framing, testing and change/design. In a simplistic way these five features bare resemblance to the cyclical elements of action research however further exploration of these theories provides helpful and specific insights. For example explanations regarding what is required for a community of practice to function are useful for a researcher to acknowledge as they provide real principles that can be actively utilised within the research setting. 'The norms necessary for this process (community of practice) include making behaviour and the reasoning behind it transparent and open to the scrutiny of others, suspending judgement and persisting in enquiry until a common understanding is reached, actively seeking information that might disconfirm one's beliefs and openly admitting error when confronted with evidence' (Friedman and Rogers, p253, 2008). These may not be the actual principles adopted ordinarily by those participating in the research therefore proactively highlighting these can enhance collective understanding and agreed ways of working between researcher and participants from the onset of the collaboration.

Theories of action are mental theories that guide our own behaviour and enable us to understand the behaviours of others (Argyris and Schon, 1978). It is evident that within action research this is a core and fundamental theory that spans the cyclical processes involved in AR. Making theories about the behaviours of others is critical in the research stage but also crucial in the change or action phase as collective understanding of behaviours will guide the processes and interventions adopted. An interesting aspect of mental theories are espoused theories, and theories in use (Argyris and Schon, 1978). Espoused theories are those that express how we think we act, theories in use are implicit in how we behave. It is evident within these distinctions that there is a need for discernment and in-depth understanding when researching with

communities. What is voiced and made explicit by both participants and researchers requires investigation and the avoidance of assumptions.

Having considered theories that relate to the conduct of action research, the next section will discuss the development of theories that arise from action research studies themselves.

### **3.6 Development of theory from action research**

Waterman et al (1995) describe a theory as formalised public knowledge, which is written down. Examples include a thesis and research reports.

Meyer (2000) argued that AR contributes to both social science and social change. She highlights the theory practice gap in clinical practice, whereby randomised controlled trials do not provide the evidence needed for particular clinical situations due to the uniqueness of these situations. AR can be one way of addressing this as it, 'draws on practitioners intuition and experience, it can generate findings that are meaningful and useful to them', (Meyer, 2000: 179).

AR outcomes and theories cannot be generalised in the same way as quantitative research, however it can positively influence practice as it relies on the reader of an AR report, to make judgements based on their own experiences and translate findings into the context of their own work. For this to take place, Meyer (2000) emphasises that it is essential that the AR report makes clear, the biases of the researcher and the context of the research. Badger (2000) argues that theories, which emerge from AR, are particularly suited to nursing, as they arise from process issues and nursing has been criticised for focussing on processes of care rather than researching direct outcomes that result from care giving. In recent policy work identifying clinical quality indicators for nursing, the Scottish Government identified only four areas for development. This limited number was the result of the absence of nursing research on direct outcomes of care and the complexity of interdisciplinary working. It proved difficult to determine what could be considered to be specifically a nursing only intervention within in-patient care settings (Scottish Government, 2008).

This is evidenced within this study, as a significant focus of activity was about the process of assessing someone for distress and or pain, and then determining how this impacts on decision-making and treatment. This study has not focused on outcomes of identifying a causal relationship between completing a particular assessment and the reduction of distress for a specific number of patients. The reason being that this is a highly individual, complex and multifactorial situation, whereby a causal relationship would be very difficult to establish. The benefit of examining the processes involved in these assessments, means that practice can be enhanced within this specific element of care and how this was achieved within the AR site can be shared with others, enabling an enhanced understanding of the process issues and theories that emerged. This can be considered by those reviewing an AR report within the context and experience of working in their own situation.

The fact that AR reflects the clinical reality of situations means that theories developed from studies can be recognised and understood by practitioners. With this said, Waterman et al (p. 783,1995) state that, 'nursing theory and practice are dependant upon one another, they seem to form a symbiotic relationship, one cannot survive without the other, and they appear to complement one another.'

Waterman et al (1995) do throw out a serious caution in regard to the development of theory and sharing this with others. They state that AR is a very complex process, this complexity is only really understood once it has been experienced by participants themselves. To clearly describe and prioritise what needs to be told to ensure a reader of AR has all the necessary information to understand a proposed theory, is in reality very difficult. Omitting key issues can obscure the reality and potentially make straightforward something that is difficult. The onus is on the researcher to clearly and honestly present the work following the robust analysis of the data.

Within this study there are many complex issues in relation to context and situation but also the care provided to and the behaviours of PWAD that will require precise explanation. Only by the provision of such information will the theories presented in this study have clear and accurate meaning to the reader. Examples of existing theories being incorporated and investigated within this research are person centred care (Kitwood, 1997) and relationship centred care (Nolan et al, 2003).

### **3.7 Participatory and democratic nature of action research**

The term, new paradigm research, has also been associated with AR. Reason (1988) described new paradigm research as a co-operative enquiry in which all those involved participate in some way to the process. Dependant upon the degree of involvement of participants, Reason (1998) argues that at the highest level of involvement, the distinction between the researcher and subject can potentially disappear.

Rolfe (1996) states that AR promotes a non-elitist approach to research, whether the scenario be an insider or outsider researcher, practitioners themselves should hold some degree of control and direction of the work itself and importantly the implementation of findings. Meyer (2000 p178) describes action research as having a, 'democratic impulse'. Namely that participants are seen as equals, the primary role of the researcher being as a facilitator of change. Meyer (2000) describes a positive aspect of this approach, being a research process and outcomes that are more meaningful to participating staff, based on their practice and within their context. Webb (1990) describes action research as a very different approach to research, not the smash and grab approach, where the researcher enters a situation, grabs the data required and then leaves again, it is about working together with participants on an equal basis. Livesey and Challender (2002) and Kemmis and McTaggart (1998) also highlight active group working in AR, by identifying that it is through the methodology of an AR approach that problems are identified and actions taken, not by the researcher independently acting as both the identifier and solver of problems. Cockburn and Trentham (2002) and Meyer (2000) reinforce this by

stating that all elements of AR should involve democratic collaboration, namely information sharing, systematic inquiry, reflection and action, with the expected outcome of meaningful social change. These are all important features of democratic and participative ways of working however there are real challenges to working democratically, when people have different levels of knowledge and experience and differing motivations for taking part. Fundamental skills such as communication can impact on how someone is able to participate.

In respect of this study collaboration, participation and involvement of staff was a key feature of the research process. The author of this paper would argue that consistent and ongoing involvement with key staff from both services directed the focus, conduct and outcomes of this research. In both participating services a core group of staff became key workers for the research. They analysed data and had an important function in negotiating and communicating with other staff as the research progressed. The focus of the action phase of the study, the assessment of pain and distress for PWAD (Almond Ward), and supporting family carers (Meadow day Centre) was selected by staff themselves and arose from identified local needs captured from the work of the West Lothian Dementia palliative Care Needs Assessment. This would be strongly consistent with Meyer's (2000) view that AR outcomes require to have meaning to staff and are based on their practice and context. Furthermore the researcher would emphasise that working collaboratively and in a democratic manner with staff, resulted in a sense of ownership and commitment to the research activities impacting on the eventual outcomes and sustaining practices.

Meyer (2000) points out that participation in AR can be significant and ongoing, not a single data collection experience, as may be the case with other research methods. The initial period of involvement and negotiation is important, as there needs to be general consensus between participants and the researcher that something is worth investigating and changing. This can be a complex process as the motivation to take part for the researcher and potential participants, may not be straightforward. It can also be difficult to know exactly what will be

involved in the research from the onset, as this may not be known. In this situation the participants may not know what they are signing up for, the most helpful agreement between these parties is to be honest regarding what is yet unknown. It is clear from literature that democracy and participation are key principles in AR. Challenges to participation and democracy will be discussed in section 4.9, ethical issues in AR.

Within this study, staff from participating services took part in the needs assessment process, the first phase of the research, and were aware of the key priorities identified. To this extent there was significant time and data collection activity that paved the way for decisions about the foci of the AR at each site. Both services identified with some certainty their chosen research focus.

### **3.8 First, second and third person enquiry in action research**

Within this research study a number of different voices are heard in isolation and together, the researcher's voice and the voice of participants. In some instances the collective voice of other people, who were not active participants but were involved in the research, are also heard. Within action research, a number of authors have focused on and identified the importance of acknowledging these voices, (Reason and Torbet 2001, Chandler and Torbet 2003).

Reason and Bradbury (2008) provide broad definitions of first, second and third person enquiry and a framework that outlines how they connect.

First person enquiry identifies the researcher as the first person. The researcher needs to develop skills in enquiry and reflexive practice, consistently analysing their own thoughts, behaviours and practices within their ordinary life as well as within a research context. Developing an understanding of how and why they react to situations. As identified earlier AR is conducted through the researcher therefore it is more of an interpersonal process than one that relies on defined and prescribed methods. The ability of the researcher to observe, critically analyse and adapt their behaviour in the moment, is fundamental to the whole action research process. It is also necessary to attain a level of

transparency about first person processes if the researcher is to facilitate an in depth understanding of the research to those reading the work. There are a number of similarities with this activity and reflexivity. Reflexivity is discussed in more detail in the next section. Within this thesis, the researcher presents first person enquiry at various points in the action research. For example first person enquiry is presented early in chapter one where the researchers background and perspectives are presented. This section incorporates information about the researcher's experiences, reflection and learning and consequent impact on practice and career choices. It was necessary to state these at the onset of the research in order to provide a basis for understanding the first person enquiry, that was to follow as the research progressed.

Examples of first person enquiry directly presented within the thesis include the analysis of participant observation during each of the case studies in the action phase. The analysis presented what was observed, the researcher's reflections on these observations but also the impact of this on the decisions, behaviour and actions of the researcher. Further examples of first person enquiry include the researcher's reflection and immediate conduct at reflection and action meetings with key staff. At these meetings the researcher and participants had the opportunity to analyse data independently ahead of the meeting and collectively during the meeting itself. The researcher's reflection and analysis of the data prior to this impacted on his behaviour. For example there were instances when the researcher's data highlighted behaviours of clients, which had not been previously identified. This situation had the potential to embarrass or undermine staff as they had been caring for the patient for a period of time and had not recognised these behaviours previously. Adopting a first person enquiry approach enabled the researcher to consider this ahead of the situation and recognise and address this potential difficulty with the staff at the meeting. Acknowledging the considerable length of time the researcher had spent collecting data from participants in comparison to the time staff had to spend with patients and observe them, required acknowledgment. The researcher would argue that first person enquiry enabled an opportunity to be aware of the



staff's potential response and actively build into the discussion an opportunity for this to be addressed.

Second person enquiry is identified as, 'our ability to enquire face to face with others into areas of mutual concern. Second person enquiry starts with interpersonal dialogue and includes the development of communities of inquiry and learning organisations' (Reason and Bradbury, p6, 2008). Throughout this study there are numerous examples of second person enquiry. This is entirely in keeping and indeed essential to the processes of participatory action research. Researching with people rather than on them to ultimately bring about social and practice related change (Karim, 2001). Examples of second person enquiry undertaken as part of this research includes; action learning with representatives from participating services, reflection and action meetings with staff, data analysis sessions with relatives and staff, audits of documentation and focus groups. As argued previously in this thesis, the large amount of second person data in this study was necessary to address the key aim of developing practice within participating services. This is a collective venture between, patients, relatives and staff, therefore second person enquiry is integral to this process of change and development.

Third person enquiry has been defined as; a practice that aims to extend relatively small projects to create a wider impact ..... a wider community of enquiry involving persons who, because they cannot be known to each other face to face..... have an impersonal quality (Reason and Bradbury, p7, 2008). Within this study there are few examples of this third person enquiry although they are present. The aims of the research, to some extent, dictate this. The research aims were focused on understanding development of palliative dementia care practice within two participating services and determining future implications for practice development and service delivery. There was no specific aim to impact on a wider group than those we were working with during this study period. There is one example of third person enquiry in this study. This relates to one of the outcomes from an action spiral at Meadow day Centre. As a consequence of data collection from clients and relatives at the

Day Centre an understanding had developed concerning the lack of cohesiveness of services working in this area and the lack of strategy to guide greater joint working. The action spiral involved Directors and Managers of the Community Health Partnership being challenged as to the absence of a strategy for dementia care. This action spiral resulted in an agreement to develop a dementia care strategy across West Lothian. This was a new initiative and a direct result of an action spiral from this study. The implications were the instigation of a wider community of enquiry where the development and implementation of strategy would have the opportunity to enhance dementia care through collective and wider learning.

### **3.9 Reflexivity in action research**

A key element to this research approach is reflection in action also described as reflexive practice (Rolfe et al, 2001), ideally both the researcher and participants simultaneously learning during the research process (second person enquiry). The authors describe this as a practitioner having their own internal supervisor, who challenges, questions and hypothesises about day-to-day practice, whilst it is taking place. It is stated that this form of learning is beneficial, developing the justification for professional practices and knowledge, exploring the whys and wherefores of intuitive practice. The overall aim is to explicitly understand and develop practice. Greenwood (1994) argues that this type of knowledge is specifically relevant to daily practice and work. Hart and Bond (1995) contend that reflexive practice is a key element in organisational improvement and provides opportunities for professionals to learn about research as they become involved and experience this process for themselves.

Reflection on action is something that happens retrospectively, where a particular situation or practice experience is reviewed with the aim of understanding the events of the situation in order to learn. Knowledge is developed through an active process of reflection on experience (Rolfe et al, 2001). The authors point out however, that this involves more than just thinking about practice, this would only recall events and may not involve an analysis and consequent action phase as part of the overall process.

With both reflection on action and reflection in action, a framework is required to guide the participant through stages of description, understanding of the current situation, analysis and then planned action, the 'now what' stage of the process. Rolfe et al (2001) discuss a macro and micro structure to reflection on action. The macro structure reflects the broad aims of the process and the key elements involved within this. They discuss the views of various authors wherein a different emphasis is placed on the outcome of the reflection. For example they refer to Fitzgerald (1994) for whom the outcome was about turning information into knowledge, Boyd and Fales (1983) however were more concerned with the participant experiencing a change in conceptual perspective and Atkins and Murphy (1994) take this further by emphasising a need for commitment to action. It is this latter form of reflection that this study would seek to achieve whereby reflection could result in a commitment to action. The micro-structure of reflection on action is concerned with the framework to be used, identifying where the emphasis lies and the trigger questions which guide the process. A number of authors have developed frameworks, such as Gibbs (1998) reflective cycle, which was developed with a particular emphasis for educators.

There are a number of ways to undertake reflection on action, written modes involve the maintenance of reflective diaries and reflecting on particular critical incidents. A more discursive form of reflection can involve one to one supervision, group supervision or action learning. The choice of which particular mode of reflection is to be used, relates to the individual situation, knowledge and experience of those involved and the resources available to them.

Within this study, action learning (AL) was initiated as a key reflective process and became a significant tool for participants from the services who took part in the research and for myself. Action learning allowed dedicated space and time to reflect on challenges and situations, but importantly it focused on participants developing their own learning and then explicitly moving to action. The continuing nature of AL facilitated a sense of ownership and accountability of

participants reinforcing working processes of reflection. Action learning provided essential reflective data for this study as each set was recorded and transcribed but each participant also completed an individual account of their learning. As discussed above this form of enquiry is known as second person enquiry.

I also joined an action learning set of people involved in practice development projects within the NHS. This allowed me a formal and safe opportunity to reflect on my experiences and develop my own learning. This data was also captured in written form and used as reflective evidence.

Regular reflection and action meetings with key staff also provided a distinct and continuing forum for reflecting on a number of issues. For example feeding back and reflecting on practice issues, the research data collected, the progress of the research and, in a practical sense, agreeing the various actions to be taken as a result of these discussions. These processes demonstrate the multiple and participative opportunities for reflexivity and analysis. Prior to these reflection and action meetings I would review and analyse the data gathered. Key staff would also simultaneously analyse data then during the meeting we would share our reflections, debate and analyse the evidence and agree actions to be taken. The benefits of this approach were the collective reflections and perspectives of different stakeholders being engaged in this process.

Reflexive processes undertaken by the researcher and participants played a key aspect of the analysis conducted throughout this research.

### **3.10 Action research cycles**

In order to understand the potential complexity and processes of AR, it is necessary to discuss its cyclical nature. Carr and Kemmis (1986) described AR as a spiral of cycles, this highlights that it is a linked process, with movement and connection from one aspect to the next. They argue that it is not a linear process with a beginning and an end, through which distinct phases are passed. The dynamism of this research approach is highlighted by Hart and

Bond (1995), as they describe it to be like a Russian wedding ring. These rings have three separate, but connected strands, and identify that research, evaluation and action are the three main components. At any given time one of these elements is dominant during action research, dependent upon the stage of the enquiry. The interplay between these three elements of action, evaluation and research, was identified by Lewin (1946) as fundamental to action research.

A challenging aspect of AR, is that the point at which a project commences, and the specific route to be taken may not be easily identified. The general direction of travel may be agreed or known but the particular actions to be undertaken may not (Hope, 1998). This can be an uncertain and unnerving starting point for those directing, co-ordinating or funding AR. Hope (1998) challenges the literature in regard to this, stating that it has underplayed the complexities during these initial stages of the process. This is also a significant issue for ethics committees as they aim to ensure the activities of the researcher will not cause harm to the public. It is difficult for such decisions to be made if specific data collection activities, and the focus of these, is not identified at the outset of the research.

Wadsworth (1998) also describes cycles within AR, these cycles are more, but not exclusively, in regard to time and moving through connected activities. Wadsworth (1998) simply describes the following activities: reflecting on a situation, questioning it, undertaking some form of fieldwork, analysis then leading on to new actions. The cycle then continues and reflection begins on these new actions and so the process continues. He argues that conventional science and research, actually follow the same processes, however the key differences lie in their separation and objectivity away from practice or real world activity and that 'old paradigm scientists', stop their investigation at a given point, which is a distinct end point in itself (Wadsworth, 1998: 19).

Another feature of AR cycles is that they can occur simultaneously and relate to different but connected actions. The reason why distinct actions are taken

simultaneously, may relate to timing, resources which become available, emerging need and how undertaking different actions may be beneficial to the overall approach. Within my own research about supporting family carers of people with a dementia, we undertook staff and volunteer training in supporting carers at the same time as we looked closely at a case study of a carer who used this particular service. The aim was to increase knowledge and awareness by means of the training, but focus on reality, context and understanding with the use of the case study.

A further complicating factor is that whilst several AR cycles can be active at any point in the research process, they are likely not to follow a synchronous path. As a result, researchers can find themselves, for example, focusing on different stages of these cycles. This can result in simultaneously focusing on evaluation and action within different action cycles. Although action cycles may be related to an overall aim, in terms of taking forward individual projects or action cycles they can be subject to change, requiring differing responses as the emphasis of the cycles fluctuate and progress. Working in this way is demanding and requires an ability to juggle the management of different yet connected work streams. Due consideration needs to be given to the ability of services to work in this way. AR activity takes place during the usual challenges and needs of providing a service.

To conclude it can be argued that the Russian wedding ring cycles, described above as balancing research, evaluation and action, can also be integral to the more chronologically focused action cycles as described by Wadsworth (1998).

### **3.11 Development of baseline understanding**

Coghlan and Brannick (2005) discuss the need to 'have a breadth of pre-understanding in order to determine the context of the action research setting. Hope and Waterman (2003) also argue that there is added value in terms of validity, when there is a comprehensive understanding of the organisation, the environment, how the organisation undertakes its work and its aims. Kemmis and McTaggart (1998) name and describe this activity as a reconnaissance

phase, where there is a need to take stock of the situation, in particular language and discourse, activities and practice and the social relationships and organisation. Coghlan and Casey (2001) highlight that insider action researchers, namely those from within the organisation, have an advantage that from the onset of the action research they are familiar with and understand the organisation at a sophisticated level. Potential challenges however, are that they may make assumptions due to their familiarity with the setting and they may be too close to the data to examine it critically.

Data collected, which enables this level of understanding, has to be rigorous but relative to a particular need. In this research the overarching objective relates to palliative care for people with a dementia, therefore particular focus will require an understanding of the needs of people with dementia and their carers, who use the services participating in the research. It will also be necessary to measure the quality of care currently provided. This can enable an understanding of what is currently positive in the delivery of care and what elements could be enhanced. To perform such an evaluation it will be important to understand the systems or processes of care currently practiced, namely how people are assessed, how care is planned and then delivered, who is involved in this and to what extent people with dementia and their carers participate in these activities.

An understanding of the working ethos of each participating service is needed in order to facilitate a relevant and realistic working relationship between the researcher and staff, with a view to planning a change to care delivery. The absence of this form of understanding by the researcher, could lead to failed expectations affecting both parties and changes to practice which are not deemed pertinent or have a lesser priority for service providers. Wallis (1999) argues that for research to have an impact on practice, a need exists to focus on problems that are unique to a local practice area. This further emphasises the benefits of being aware of local needs and the usefulness of completing the needs assessment as a platform for meaningful research. Over and above this the changing nature of the researcher's role from outsider to more of an insider

within this study enabled a sound understanding of the participating services how they worked and relationships amongst staff.

For those who read action research studies it is important that this level of context is presented in order to allow judgements and conclusions to be made regarding the findings and identified theories of the research, as well as determining how the research findings are relevant to their clinical practice area.

The specific research methods used to determine a baseline understanding will be described fully in chapter five, together with an analysis of the results.

### **3.12 Issues of validity and reliability in action research**

In general research terms a method is thought to be valid if it measures what it sets out to measure (Parahoo, 1997). There are a number of other, more specific issues in relation to validity, described as face validity, content validity, internal and external validity, each of which is concerned with a particular aspect of this phenomena. In regard to AR, Greenwood (1994) claimed that AR relies solely on face validity, that there is an apparent fit between the research methods used, the result and the context of the research situation.

Parahoo (1997, p38) described reliability as, 'the consistency of a particular research method in measuring or observing the same phenomena'. Reliability is also broken down into component parts, such as inter-rater reliability. Inter-rater reliability refers to the degree of consistency a measure achieves when used by different people to monitor the same phenomena. Should two people, using the same measure to record the same phenomena, establish identical results, the measure would be deemed to have excellent inter-rater reliability.

Within this study a number of assessment tools were introduced into practice. These had been through varying degrees of testing in their development. The Disability Distress Assessment Tool (Regnaurd et al, 2006) is used to determine whether someone with communication problems is experiencing



distress, it's reliability had been directly assessed and reviewed in the literature. A number of tools were used during the action phase of the research, to assess changes to practice. An example of this was an audit tool that focused on the recording of pain care within patient documentation. This audit was developed in conjunction with staff from the service and in relation to the particular documentation used by this service. In terms of the face validity this method would be regarded as high. In terms of reliability, the measure was piloted then adapted. This involved changing some questions and process points. The measure was also used at different points in the research and by different people to measure the same phenomena in order to compare care practices at different time points. The researcher and members of staff reflected on the content and process of using the audit tool. The efforts described here identify that a degree of testing for reliability of the audit tool were undertaken in this research. A more rigorous approach would have been to test it on a number of occasions within different settings with different groups of staff and rigorously compare results and reflect on the process.

Although face validity has been identified as important in action research (Greenwood, 1994), dependant upon the measures of evaluation and who is conducting these, reliability can also be relevant. It could be important, for example, that a method of evaluation provides a consistent process over time and when used by different people. An audit process reviewing documentation of pain assessment and management used within this research serves as an example of an intervention that required effective validity and reliability.

Argyris and Schon (1991) discuss differing priorities in regard to the approach to scientific rigour used by Action Researchers. They argue that the proponents of AR are less interested in the scientific rigour of their work; rather they focus on the methodology and its usefulness to participants. Bowling (1997) however challenges this by saying that action researchers demonstrate rigour by triangulating their research methods. Within this research a multi method approach was used to understand phenomena from different perspectives. Different data collection methods were necessary; as participants had varied

abilities, the methods used had to reflect their potential ability to participate. There was also a need to use different methods to evaluate and understand interventions, the aim being to develop an understanding, as close to reality as was both feasible and practicable. Specifically an example of this was the use of interviews with staff and family members and participant observation with people who have a dementia to examine the same research issue but from different perspectives. The overall purpose being a true understanding of the situation under investigation but also to provide readers of the research with a breadth of relevant evidence to enable understanding, judgement and where relevant potential utilisation of findings.

Establishing validity has been described as difficult to achieve in AR, it should be established through self-validity, participant validity and peer evaluation Ellis and Crookes (1998). This reinforces previous arguments highlighted earlier in the chapter, which stated the importance of reflection, not only on the part of the researcher but all participants. Engaging participants in reflection, in this case a range of staff and families, required time in the form of direct contact with the researcher, the provision of information that guided reflective processes, positive role modelling and flexibility. To realistically involve families required meeting them at times and in venues which suited them, often in the evening whilst visiting appeared to be a preference. Role modelling involved the researcher having a degree of openness, for example being upfront when not knowing the answer to a question or feeling uncertain about an aspect of analysis.

There is also an ongoing need to review, analyse and determine action in response to data collected, at all stages of the AR process. The literature above also points to a need for inclusivity during all of these stages in the AR process. In terms of rigour, these methodological issues appear to be key and require to be established early on. McNiff (1988) argues that it is the fact that a systematic enquiry is made public, which distinguishes AR as research, it is the manner in which it is conducted and made known, that is important.

From a more radical standpoint, Meyer (1993) and Hart and Bond (1995) do not discuss issues related to either reliability or validity in AR. They focus and prioritise reflexivity as the key issue of scientific rigour, akin to scientific rigour demonstrated within qualitative research approaches. Waterman (1998) however has explored validity in AR in more detail and depth. She identified three categories of validity in regard to AR, these are dialectal, critical and reflexive validity. Waterman (1998) described dialectal validity as the constant analysis and report of movement between theory, research and practice. This necessitates both the describing and examination of tensions and complexities within a situation. Critical validity, her second criteria, focuses on specifically examining the process of change, not the outcome of the degree of change that occurred, rather the intentions and actions of participants and the consequences of these. Reflexive validity is the researcher's recognition and exploration of bias and the consideration of interpretations. From my analysis of these three criteria, they all, in reality, describe how to be reflexive and Waterman in effect provides a framework for this reflection, namely the specific issues reflexive practice should address. Waterman (1998) in this aspect is in agreement with Meyer (1993) and Hart and Bond (1995) of the explicit importance of reflexivity in regard to the methodological rigour of AR. The figure below identifies how one method of data collection used in this study, reflection and action meetings, incorporated Waterman's framework but in reality were reflexive processes.

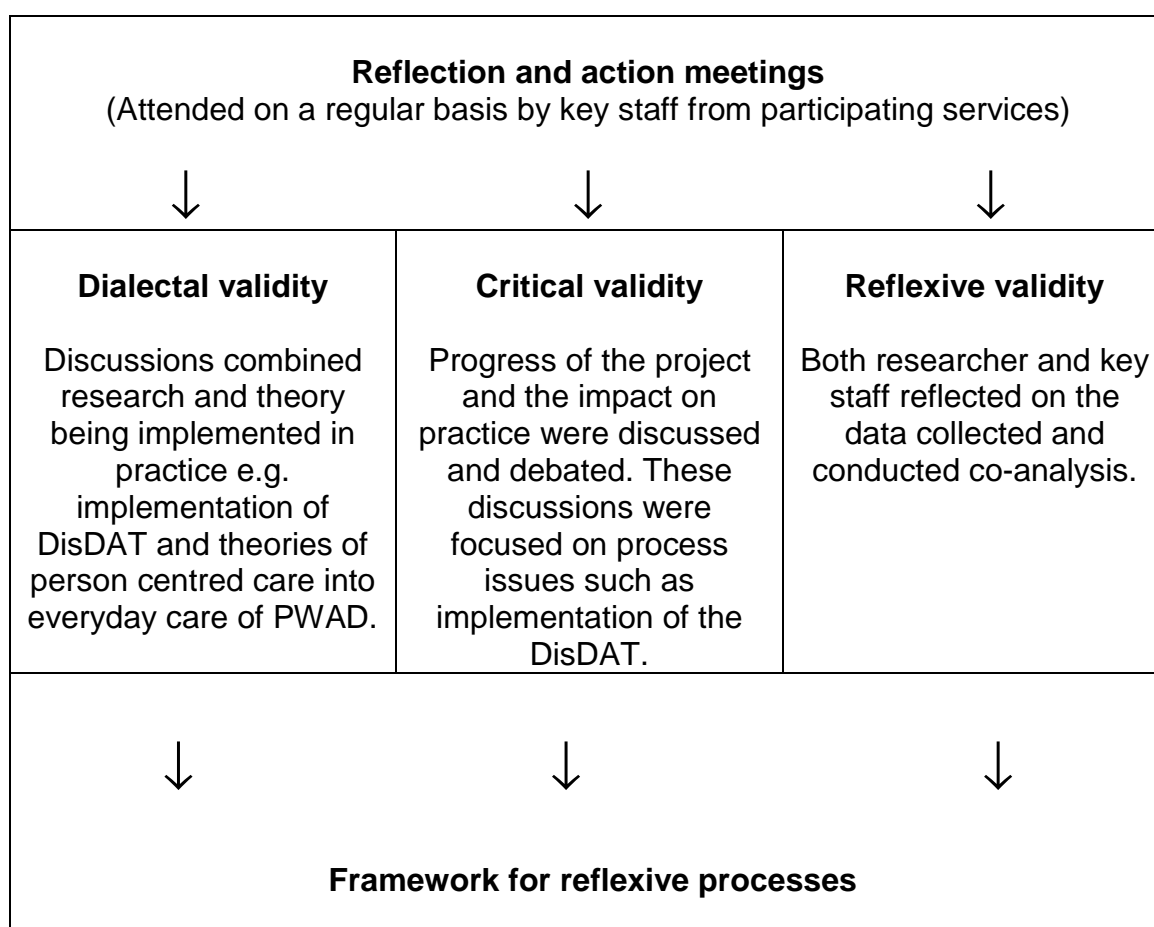


Figure 3 Framework for reflexive processes

### 3.13 Ethical considerations of action research

There are a number of general ethical concerns to consider when undertaking AR, however within this specific research, there are also important ethical issues to consider in respect of including people who have a dementia and their carers, these will be presented in the next section. Williamson and Prosser (2002) point out that in general, research ethics relates to such issues as confidentiality, maleficence, beneficence, informed consent, right to withdraw, honesty and integrity of data handling and analysis. Within AR these issues become focused on the close relationship between the researcher and participants and the explicit aim of changing practice (Lathlean, 1996).

In terms of the ethics of undertaking AR in general, gaining consent from participants to take part is in itself an ethical issue. From the onset, efforts can be made to inform as many people as possible from the participating area about the research and gain their consent. Within this research this involved written material being made available to staff in the form of posters about the study and the distribution of information letters. Numerous meetings were held with staff to discuss the study and go through information letters and sign consent forms. Numerous meetings were required, as it was necessary to discuss the study with as many staff as possible when they were at work. Due to the fact they all worked different shift patterns, this meant seeing two or three staff at a time, within this study and in particular within the in-patient ward, this was a very time consuming process.

When there is uncertainty, in respect of what will be done as part of the AR, it can be difficult for participants to know what they are signing up to and fully understand the potential implications of the work to be undertaken. In regard to action spirals and the notion of continually investigating and examining practice and agreeing to introduce interventions, it is likely that a number of issues will be raised, some anticipated and some not. Although at the onset of the AR, the general area of investigation can be agreed, issues that arise can be both unexpected and potentially unwelcome and the actions taken not what was originally anticipated. Actions taken to address these ethical challenges, can include highlighting the uncertainty of the AR process to participants at the onset of the work and the critical area of negotiating and agreeing all elements of the AR process. By focusing on these process issues at the point of initiating consent, it can provide an early example of an open and honest way of working, demonstrating ethical principles.

It is necessary to highlight how professional boundaries can impact on AR and particularly the role of the researcher. In this study I was the researcher and I am a nurse. The Nursing and Midwifery Council (NMC) Code of professional practice direct my professional conduct. Should I have witnessed practice that was below acceptable standards, negligent or abusive, within the code of

professional conduct, I would be required to report this and take an appropriate form of action. This would necessitate the needs of the patient taking precedence over research activity. It is clear that patient care takes priority over a research process. If a researcher, who was not a nurse, had conducted this research they potentially may have less awareness and knowledge of acceptable standards of nursing care and therefore apply different standards. Their guide to practice may be related to civil law and a general sense of expectation of standards of care. Commonly things are seldom cut and dry and poor nursing care can appear on the edge of what is acceptable rather than definitely classified as abuse or negligence. This highlights further the need for a highly professional, honest and open relationship between researcher and practitioners allowing difficult scenarios to be addressed and action taken. These situations necessitate the need for robust reflection and co-analysis processes to validate both findings and any actions to be taken. Some participants in the research were also nurses and similarly were required to adhere to the NMC Code of Professional Conduct. Agreeing actions to be taken and increasing a sense of responsibility and ownership for participants as the research progressed, are other examples of the movement of professional boundaries and their impact on AR. For example staff undertook interventions independently such as staff training and audit activities.

It is necessary to discuss the credibility of the researcher. As stated earlier, AR is conducted through the researcher; therefore it is primarily an interpersonal activity (Meyer, 1993). Issues relating to the credibility of the researcher are important to discuss, as it is through this person that facilitation of the AR process takes place, involving their values and judgements about research findings but also about how the research process is conducted. There is a need for the researcher to exercise sensitivity and conviction through the many inter-professional relationships encountered during the course of a study. Within this study I would argue that the following factors ensured that I had suitable credibility to be an action researcher in this study. I had worked as a nurse for nearly twenty years, in a variety of capacities including posts in research, quality enhancement and management. I had specialist knowledge in palliative

care and although I had not worked to any great degree with PWAD, knowledge of dementia had increased since commencing this AR study. I was also a registered mental health nurse and had practiced in this field. In terms of personal characteristics that would identify credibility to conduct this research, I would suggest that I sought to show respect and thoughtfulness to PWAD, carers and staff. That I would endeavour to actively provide positive feedback, as well sign posting areas of concern. That I would act as a role model in my work with PWAD, carers and staff and specifically for staff, act as a facilitator to ensure they had development opportunities through participation in the action research. The extent to which staff participating in the research acknowledged these personal criteria, would be measured by their participation and engagement in the research as it progressed and their views on the research process. In particular issues such as honesty, inclusion, facilitation and a sense of empowerment.

Feeding back difficult information to service participants in an honest and respectful manner is a key challenge of an action researcher. It is inevitable that in any AR study, behaviours and practices that do not meet acceptable or desired standards will be encountered. Service improvement is one of the key reasons for conducting AR therefore this situation is both anticipated and normal. A further challenge is negotiating the complex inter-relationships encountered between participating staff. This could be argued as becoming more complex over time as the researcher naturally develops their own relationships with staff and awareness deepens of difficult relationships that can have a direct impact on the outcomes of the AR.

Within this study the researcher adopted the following strategies in order to achieve an honesty and reality to the research. It would be reasonable to state these strategies developed more consciously over the period of study as a result of ongoing reflection in action and experiencing challenging relationships. The researcher worked continuously with a core group of staff and therefore aimed to develop strong, consistent working relationships based on the premise that our purpose was to enhance care practices. Wherever possible praise was

actively given for positive work and development. Where concerns were evident the researcher aimed to clarify these and avoid making assumptions. Concerns were stated sensitively without attributing direct blame; a view was actively held that we were all participating in a learning experience, including the researcher. Within the research it was useful for the researcher to acknowledge when he had made mistakes and be explicit about his own learning and development. The researcher actively sought to value and develop participants, this involved challenging them to undertake new activities and taking opportunities to show appreciation for their work and commitment. In reality all of these strategies were useful to a degree, but within any human relationships challenges and difficulties were definitely experienced during the study. There was benefit in knowing the participating services having undertaken specific baseline investigations and developing a progressively insider view. I would argue that activities that highlighted the participants' ownership of the study such as action learning, democratic processes to agree activity and a shift towards staff taking the lead in interventions aided an honest and real approach particularly in regard to the work being sustained.

A common experience with action researchers is change of staff and participants within the area where the AR is conducted (Meyer, 1993). This can result in numerous and ongoing discussions with new staff to the area, informing them of the work and gaining their consent to take part. On another level, this could be viewed as a healthy approach to an ongoing consent process, as it means the issue of agreeing to participate in various aspects of the research is under continual negotiation. AR is known to be a time consuming process (Karim, 2001) and the longer a particular project takes, the more likely it is for staff to change or leave the area.

It can also be difficult for individuals within participating organisations, to withdraw consent if they become uncomfortable with the developments of the AR or feel it is no longer appropriate for them to take part. Despite the claims of AR stated above, such as equality, breaking down barriers and people working in a collaborative way, as the research progresses issues of power and



relationships can come to the fore. These issues can be challenging and difficult to address (Hart and Bond, 1995). Literature highlights that potential conflicts are associated with those who are driving change within the AR. This could be the researcher, managers or research steering group, staff or clients, they can all come into conflict in regard to the direction the AR process is taking. They each may have different motivations and priorities for actions and the choice of methods used. Hart and Bond (1995) are critical of the notion of collaboration in AR and have referred to it as a possible means of subtle exploitation. It is important therefore to be conscious of these potential issues throughout the process and for all parties to be actively encouraged to voice concerns and opinions and, as far as possible, own the data and the ongoing decisions that are taken (Williamson and Prosser, 2002). Within this study the researcher had to consider the complexity of being managed by the same managers as those responsible for Almond Ward and, at the same time, was also working at a senior level to ward staff, therefore a careful balance was required between working democratically with staff and being seen to represent the view of managers. This situation again highlights the importance of continuous co-reflexivity between participants and the researcher in order to jointly review these complexities of relationships and power.

Maintaining anonymity when reporting on an AR project can also be challenging (Lathlean, 1996). If the AR is done in a specific setting or is of a small scale, it may be very challenging to ensure the anonymity of certain people, particularly if they have a unique and highly visible role within the area, for example the chaplain or charge nurse of a hospital ward. They may not be named in reports but there is the potential for many people to know who is being referred to. This may be one reason why difficult aspects, such as those discussed above, relating to the challenges of conducting AR are not routinely reported within literature. The potential learning to be gained from discussion of tensions and power relationships within AR projects, although helpful for other action researchers to understand, may present too high a risk of participants being identified.

It is necessary to consider how action research projects end and how the action researcher exits the research setting. The challenges identified (Lathlean 1996, Livesay and Challender 2002), are that services participating in the research will have had the involvement of an action researcher, researching their practice, facilitating and evaluating change according to the needs and wishes of the service. This can be a positive development situation for both the researcher and the participants and it can be difficult to end. The fear is that developments and innovations may cease, that a dependency between the action researcher and participants develops but also it may be difficult to know when to stop, taking into consideration the ongoing and cyclical nature of AR.

I would argue that within this study a number of factors both signalled and enabled the end of the AR. The AR, in accordance with the parent project, had a time limit in regard to its funding hence the end date was clearly visible and regularly identified through the process. In reality the project was extended by six months so even in this time limited scenario boundaries can change. Work plans including the aims and objectives of action cycles highlighted end dates facilitating closure of AR activities. During the last four months of the study participants were facilitated to think about continuation strategies such as continuing their action learning and pursuing individual supervision arrangements. From the commencement of the action phase the researcher had specifically facilitated participants from service to lead and undertake AR activities, such as audits, conducting values clarification focus groups and routinely participating in the collection and analysing of data. The author would argue that through participating in AR an empowering process had occurred amongst participants enabling them to continue their work with new skills of research, action and evaluation. This would be in keeping with action research being identified with critical theory and feminist approaches in that the overall aim is social change through empowerment of participants (Karim, 2001). The experiences of this research in relation to these issues will be discussed in chapter eight.

### **3.14 Ethical considerations of research involving people with a dementia and their family carers**

It is very important to consider the ethical issues of involving people who have a dementia and their family carers within this AR. This research was given ethical approval by the Multi-Centre Research Ethics Committee for Scotland in June 2004. This is the committee within Scotland, which is specifically responsible for the ethical approval of research involving people who may have any form of mental incapacity. In some respects, the smooth transition of the ethical process for this study was unexpected, in that the methods of data collection had to be assumed and were not confirmed at the time of the application. In fact the specific focus of the study had not been agreed other than it would address an aspect of palliative care for people who have a dementia and that it would involve changes to practice aimed at enhancing care. The potential vagueness and lack of specific detail of this research proposal, as identified in the ethical application process, could have been subject to weighty criticism and amendment, however minor changes were requested and the overall AR approach was accepted.

Two features of the ethical involvement of people with dementia and their family carers were first, the role of gatekeepers in accessing participants and secondly, continuing negotiation and identification of consent from participants themselves or if this was not possible, from their identified gatekeepers. Staff from participating services acted as gatekeepers initially, in that from the onset of the research they discussed and agreed the data collection methods with the researcher and then suggested potential participants from their own service, who they felt may be appropriate to participate. This approach aimed to ensure that only PWAD and family carers, who staff felt would be able to take part, were approached. This process used the current knowledge and awareness staff had of individuals and their particular circumstances and arguably provided a sensitive approach to recruitment. This was an active and ongoing process, as clients of services were deliberately not approached for specific reasons, such as family carers showing evidence of stress or amidst particularly difficult situations. It could be argued that this approach may have

been restrictive and reduced the numbers of potential participants, and also employed a paternalistic stance to recruitment. The participation that was required however, involved a small number of PWAD and family carers to take part in case studies. These case studies were of an in-depth nature and required continual involvement over a period of weeks. They also necessitated families to consider potentially difficult and sensitive issues such as distress, pain and the impact of dementia on the affected person and their family. The key issue of recruitment therefore was not to identify large numbers of people, but PWAD and their family carers willing and able to participate in an ongoing and in-depth investigation.

The second feature of ethical involvement, as mentioned above, was that of continuing negotiation and identification of consent from participants themselves or if this was not possible, from their identified gatekeepers. In terms of family carers this was more straightforward and involved specifically identifying at the first contact, that they could withdraw at any time without providing a reason and that the researcher or member of staff would ask them whether they wished to continue to participate at each stage of involvement. For people with dementia this process was more involved. If the person was unable to consent this responsibility fell to their next of kin. PWAD were involved in two elements of data collection, interviews and participant observation. The interviews, part of the initial needs assessment, were with people who had mild dementia and the majority were able to consent, if not their next of kin gave written consent and the PWAD verbally consented. On the majority of these occasions the family carer was present during the interview.

The PWAD who took part in participant observation were unable to give either written or verbal consent. These participants had severe dementia and were identified by staff as in pain or distress or their dementia was having a significant impact on their family. The staff initially suggested their involvement and then family members/carers were approached, first by the staff, then by the researcher. The participant observation, part of a case study approach,

ensured that family members/carers and staff were closely involved in the process and were therefore able to monitor what was happening in terms of the participant observation and the reactions of the PWAD. The family met the researcher at the beginning of the case study and took part in an interview, they would see and comment on the notes generated from the participant observation and have a second and final interview after the participant observation was complete. At the discussions of consent with the family member, they were informed of the following strategies that would be in place to ensure the PWAD did not experience any additional distress or be disadvantaged in any other way as a result of participating in this research:

- The participant would receive their usual care, the researcher would observe this whilst also taking part in delivering this care.
- The researcher would work alongside or be supervised by a member of staff known to the participant.
- This member of staff and the researcher would observe for and respond to any additional distress or other adverse reaction to the PWAD as a result of taking part in the participant observation.
- Should additional distress or another adverse reaction be identified, the participant observation would stop.
- The researcher would familiarise himself with the usual care provided to the participant and assist in the provision of this.
- The researcher would record observations by means of a dictaphone and this would be done discretely, without drawing attention or causing annoyance to the PWAD.

From the above points, it could be identified that a number of issues may have reassured families that the PWAD would not come to any harm as a result of taking part in the research and hence positively influenced their provision of consent. They had a chance to meet the researcher and make judgements on his suitability for this work, the staff were supportive of this research and therefore it was probably deemed worthwhile, both they and the staff would be actively involved in the process and be able to see and comment on what was observed and voice their opinions on the issues at hand, nothing 'out of the

ordinary', would be done to the PWAD, and there were sufficient checks in place to stop the process, should it appear to be causing a problem to the PWAD.

Justifiably there was a significant degree of focus, thought, consideration and time given on the part of staff and the researcher, in regard to the ethical issues of involving PWAD and family carers within this research. It was unacceptable to all parties involved, that a research process, aimed at practically enhancing palliative care for PWAD and their families, should actually cause any undue harm or adverse reactions whilst it was being carried out.

### **3.15 Description and justification of methods used in this research**

#### **Sampling and recruitment**

A number of issues related to sampling and recruitment of PWAD and their carers have been discussed above in section 4.10 of this chapter titled, ethical considerations of research involving people with a dementia.

Sampling and recruitment of service providers is described in detail in chapter six, section 6.3 and 6.4.

In summary, purposive sampling was used in this study, namely participants were selected on the basis that they met the purpose of the research. This related to both service providers and service users. Service providers were required to operate within the defined geographical area of the research, West Lothian in Scotland and to actively provide a service for PWAD. PWAD and carers selected to participate were those who used those services participating in the research and who were experiencing the problems under investigation, namely PWAD who, in the view of staff caring for them, were experiencing pain and or distress and carers of PWAD who had support needs.

The aim of the action phase was to gain an in depth understanding of the research foci from the perspectives of PWAD, their family carers and service providers and directly

### Use of multiple methods

It is common for multiple methods to be adopted in an action research project, the reason for this being the need to understand a situation from a variety of perspectives but also to understand a situation in a comprehensive way taking into consideration the context and setting. Action research, at some stage, also involves some form of evaluation and this may again require a need for a variety of methods to be used. Meyer (2000) called AR an eclectic approach to research due to the use of multiple data collection methods. Within this research study there was a need to understand the perspectives of PWAD, their family carers and staff from participating services as well as how services were provided, what did the staff want to change and why, and how would it be determined what differences had been made to the service. This involved a number of data collection methods such as interviews and participant observation. There was also a need to gather and analyse different types of evidence, such as documentary information from patient notes.

Conducting multiple data collection activities, amidst different care settings, involving a range of staff, PWAD and carers and at the same time tackling different topics such as the assessment and management of pain and distress for PWAD, and supporting carers of PWAD, resulted in a very complex study. Multiple issues and perspectives require triangulation, consideration and explanation. As much as I would concur with Meyer's (2000) aspiration of understanding the research issues in a comprehensive way taking into consideration context and setting, the complexity of undertaking this form of research requires to be highlighted. This is not a clear linear research process but a messy journey that twists and turns and requires continual review, negotiation and forward planning. Given all of these considerations the experience of the researcher to undertake such a study requires consideration, particularly in view of the fact that this is an emerging process, not necessarily clear from the onset.

## Interviews

Interviews were used in this research to identify and explore the perspectives of key participants, namely PWAD, their family carers and staff and volunteers from participating services. Interviews were used in the initial needs assessment process and then at various stages during the action phase of the research. For example during the action phase, families of PWAD were interviewed on two occasions, the first interview was conducted prior to participant observation with their family member and the second interview after the participant observation was completed. The first interview explored their views of the subject under investigation and the second focused on their impressions of the written reports and feedback of the participant observation. The first interview adopted a semi-structured approach and the second had an identified aim but was open in structure. The majority of interviews however were semi-structured.

All interviews during the action phase were audio taped, the researcher listened to the tape and made notes into a dictaphone. A secretary typed a report from the dictated notes and the researcher checked the typed report for errors in



dictation and typing. The interviews were not transcribed in full for the following reasons: there were too many interviews conducted throughout all of the research (five services in total) and the amount of data produced by transcribed interviews would have been overwhelming; there was a real need to be pragmatic and give consideration to the families and staff who would read these reports and the time they had available to undertake this continuous analysis process: large transcripts of interview data may have been daunting for participants and actually inhibited processes of analysis as they would not have experienced this process before: the overarching purpose of interview data was to understand, enhance and impact on care practices, not analyse the minutia of research interview data as may occur in other research approaches such as discourse analysis for example.

A pragmatic approach was therefore adopted to balance the quality and quantity of data gathered. Reports of the interviews were sent back to the participant, requesting them to read the report to check its accuracy but also to consider any changes or additional comments they would like to make. The researcher then made contact with the participant, usually by phone, to complete this process. The researcher then analysed the interview report, drawing out key points made by the participant and reflecting on the interview as a whole. This analysis and reflection of the interview was commonly used as the basis of the reflection and action meetings held with key staff from participating services. The analysis was inductive in that it incorporated findings from other data, gathered previously, and assisted in building a developing understanding of the issues under enquiry.

#### Reflection and action meetings

Reflection and action meetings were held regularly with key staff from the participating services. The key staff included the manager of the service and one other member of their staff. The staff members had a particular responsibility or interest in this research. At different points in the research new members joined these meetings however the core group remained static. New members included students of nursing and social work but also other

permanent members of staff. Inclusion of new members was to provide an educational experience but also to engage with staff when a particular phase of the research was undertaken, for example where training was being cascaded out to staff. These meetings took place regularly, usually monthly their aim was to represent the heart of the collaboration between the researcher and the participants, as Meyer (1993) would have described it, the democratic pulse of the AR. These meetings would serve a number of functions as follows:

- Research data was analysed and debated
- Views were expressed regarding the progress of the research
- The actions to be taken were agreed
- Data collection and evaluation methods were agreed
- Barriers to the research were identified.
- Roles and responsibilities were identified and agreed
- Participants were identified
- Communication approaches were identified and delivered, engaging PWAD, family carers and staff from the service.
- To provide a focus, a way of motivating staff and a momentum to the research

At these meetings written notes were taken, they were then dictated and minutes were typed. The minutes identified the key points discussed and decisions taken, specifically stating who had responsibility for particular actions. The minutes were then sent to the key staff, by Email. At the following meeting the minutes were checked, discussed and a new agenda agreed.

### Case studies

A case study approach was used to undertake an in-depth investigation of the experiences of PWAD, their family carers and the staff and volunteers who worked with them. The aim of the case studies was to review a real life snapshot of the issues under examination and identify potential learning. Hart and Bond (1995) identified that the learning from the presentation of case studies can occur at different levels. 'Each of the case studies, in a different way, illustrates that in action research generalisation can take a number of forms,

including using the findings from one project to initiate another, and extending what has been learned to a different setting ..... a practitioner audience for action research might recognise similarities with their own situation, so that comparisons of more general relevance to practice are made. Such a comparative approach, particularly where it presents the practitioner with detailed, descriptive ethnographic data, may be used to evaluate one's own practice, and can prompt further action for improvement' (Hart and Bond, p10, 1995). Learning can therefore be identified as individual, practice and organisationally based, an important factor however is the provision of sufficient contextual information to enable such learning to take place.

Meyer et al (1999) conducted a study that compared findings from a single case in relation to those from a systematic review of action research. The focus of comparison was the process issues related to changing health care practice, specifically identifying barriers to change. The conclusions from this study were that the nine barriers for change identified within the single case were replicated in the systematic review (75 studies that met the criteria of being action research and focused on change within a health care setting). Meyer (1999) concluded that, whilst it is not possible to generalise directly from a single case study, within this example findings appeared to hold true within other health settings. Meyer argues that confidence in action research case studies should be increased as external validity can be raised due to the research being conducted within the realities of practice. It would be important that this research is replicated in order to further the claims of the author about the external validity of case studies conducted as part of an action research study.

In their book, *Action Research for Health and Social Care* (1995), Hart and Bond use five case studies to highlight key themes related to the conduct of action research. In a similar way, within this research the case studies are illustrative of the subjects under investigation, namely supporting family carers of PWAD and the assessment and management of distress for PWAD. Within the community hospital setting the case studies focused on PWAD (patients)

who were, in the opinion of staff caring for them, experiencing significant pain and or distress which was difficult to manage. The case study involved two interviews with the families of these patients, one prior to and a second interview after a period of participant observation with the patient, participant observation with the patients themselves, review of the patient's documentation, discussions with staff and the examination and completion of a formal assessment, namely the DisDAT assessment tool. Within the community hospital setting two such case studies were undertaken.

Within the day care setting, one case study was completed using the same process as described above. In this instance the subject of the investigation was the experience of the family carer, particularly focusing on their needs and the existing support provided to them. On this occasion, The Carer's Checklist, an assessment tool for carers of people who have a dementia, was examined.

#### Participant observation (PO)

This was discussed above in section 4.10, but involved the researcher providing the usual care or service to the identified patient and or client for an agreed period of observation. Patients in Almond Ward were unable to participate in an interview, as their dementia was too severe in nature, therefore this approach aimed to first describe their experiences from the perspective of an observer and then analyse the meaning of these observations, in an active attempt to view the situation from their perspective. The PWAD observed in the day care setting (Meadow Day Centre) did have a limited ability to engage in discussion, despite the severity of his dementia. The PO process in both settings involved observing their actions, behaviour, speech and vocal sounds taking into consideration their interactions with staff and fellow patients and the impact of the environment upon them. To an extent, it could be argued, that there was an ethnographic aspect to these observations as they attempted to look at and describe the whole situation including the social context of the service.

The researcher used his skills, experiences and knowledge to shape these observations, therefore they were unique to him and required to be understood within this context. As described in section 4.9, earlier in this chapter, the researcher had knowledge and experience that provided an appropriate level of competency to undertake participant observation. Experience in nursing, both mental health and palliative care ensured fundamental aspects of care could be provided but also observations and interpretations of behaviour had been a core aspect of the researcher's practice for many years. The researcher had undertaken research training during a Bsc in Nursing Studies and at Masters degree level, but also had gained experience working in a research and quality enhancement post. In terms of working with an understanding of dementia care, the researcher had acquired new knowledge as a result of completing the needs assessment process described in chapter three. This new knowledge incorporated a broad and comprehensive awareness of experiences from the perspectives of PWAD, their carers and service providers. From research literature and contact with leading dementia care practitioners (part of the broader project steering group) an understanding of the physiological and psychological impact of a dementia related illnesses had developed.

The observations did not follow a specific schedule or criteria such as takes place in the Bradford Dementia Centre's dementia care mapping process (Kitwood & Bredin, 1992), but they did have a general focus of enquiry. Within the community hospital setting, observations particularly focused on the patient's experience of pain and or distress, how this was manifest, and what potential things made these problems better or worse. Three distinct periods of observation took place with each of these two patients in the community hospital. The periods of observation lasted between three to five hours each in duration. The first and second periods of observation took place on consecutive days, the third being three weeks later.

In the day care setting, observations focused on the client's thoughts and behaviour in regard to his situation and his need for carer support, particularly that his wife was now his main carer at home. The focus was how he

recognised this situation, and what, if anything, it meant to him. Due to residual, but limited verbal skills, talk with the client was possible and therefore included as a part of this period of observation. Talks with the client did not follow a form of interview; rather it occurred around day care activities such as looking at family photos and taking part in craft activities such as painting. Discussions followed an indirect approach, asking him questions about his activity and how he responded to what he was doing. Four distinct periods of observation took place with this client at the day care setting. The periods of observation lasted the length of a day care period, namely 4-5 hours and took place at an interval of once a week for a total of 4 weeks.

The researcher recorded his observations on a dictaphone, at various points during the period of observation. This dictation was later typed into a report and in a similar process as described above, the report was shared and discussed with the family carers of the patient and the staff and volunteers from the service. The reports formed the basis of the second interview with the family carers and were the focus of reflection and action meetings with key staff. These reports were however made available to all staff from the appropriate service and a copy was placed in the patient's notes to be an active part of their records.

### Action learning

Action learning could be described as both an intervention and a research method. An intervention in that it was a new practice initiated to support participating staff in this AR, but also a method in that it generated evidence.

Action learning is defined as, 'a continuous process of learning and reflection, supported by colleagues, with an intention of getting things done....Individuals learn with and from each other by working on real problems and reflecting on their own experiences...The process helps to take an active stance towards life', (McGill and Beaty, p11, 2001)

One key member of staff from each of the five services participating in the parent project were invited to attend monthly action learning sets. The sets

were facilitated by an external person to the project, experienced in the facilitation of action learning. Funding to replace key staff was made available to participating services to facilitate attendance at action learning. The aim of the action learning was to encourage key staff to have ownership of the work within their own service and to receive structured support as identified in the definition of action learning above. The objectives of action learning were agreed as follows:

1. In accordance with the foci of the project, participants will use action learning to address the following issues related to people who have a dementia: pain assessment and management and supporting carers of people who have a dementia.
2. Through an action learning approach, participants from each service will be enabled to reflect on current practice.
3. Through challenge and support, participants will learn from their practice, and in response to this, identify and undertake actions within their workplace.
4. The action learning set will provide a means for participants to share and learn from one another's experiences and services.

The outcomes of action learning were identified through the following: at the end of each set, participants completed an evaluation identifying, amongst other things, actions they wanted to take and what their learning had been. The sets were audio recorded and notes typed and then distributed to each participant, providing an account of all aspects of the action learning. The facilitator also completed a reflection, stating issues such as the progress of the set to reflect on their practice. As described above, action learning was one of the processes involved in second person enquiry.

The researcher also participated in action learning and joined an action learning set consisting of nurses and facilitated by a sociologist experienced in action learning. These monthly sets provided a forum for the researcher to reflect and act on issues he felt were important to the AR. The researcher made notes

following these action learning sets as a way of identifying reflective work undertaken throughout the research.

#### Review of patient / client documentation

Reviews of patient / client documentation were conducted for several reasons: first to understand the existing assessments and care planned for those patients / clients and family carers participating in specific case studies. Secondly they were used to evaluate the impact of implementing new assessments conducted by staff, namely the Carer's Checklist (Meadow Day Centre) and the DisDAT (Almond Ward). This took the form of pre and post intervention audits of documentation. Audit processes and documentation were developed in conjunction with service staff and specific to the client documentation processes used by participating services. One of the main objectives of reviewing documentation was to triangulate evidence with other data collection identified above and capture a comprehensive and real understanding of the situation.

#### Data analysis process

An aim of the data analysis was that it would be a continuous process throughout the action phase and that this would involve, where possible, all participants: the researcher, PWAD, family carers and staff. A process of analysis occurred after each data collection activity that took place. Due to the multiple data collection activities undertaken; this resulted in a continuous process of analysis. There were several reasons for adopting this continuous and participative process, these included: a need to capture analysis from different perspectives and, as far as possible, validate the findings and analysis from the perspectives of key participants; to ensure an iterative process where there was progressive dialogue and debate with key participants; to continually build on analysis and meaning incorporating new evidence in a systematic and progressive manner; to continually capture, reflect upon and evaluate the implementation of changes to practice in light of previous analysis and to inform future actions as the research progressed.



In order to highlight the above points, an example is provided of the data analysis processes that took place as part of the case studies undertaken within Almond Ward.

Data collection activity	Analysis process
First interview with carer	Interview was audio recorded and typed up. Initial analysis conducted by researcher using Microsoft Word - key themes highlighted from written text and quotes / data copied and pasted and organised according to key themes. Interview sent to carer to check for accuracy, and consideration of any additional comments / thoughts. Carer contacted by phone to discuss this.
Reflection and action meeting	Carer interview discussed and analysed with key staff from ward at reflection and action meeting. Researcher presented interview report and initial analysis and key staff debated themes in light of their knowledge and experience within the context of the ward. Meeting notes typed incorporating discussion of analysis and sent to key staff. Analysis document updated in light of discussion.
Episodes of participant observation with PWAD in Almond ward	Observations recorded on Dictaphone during the period of observation (e.g. at meal breaks) then typed into report. Key themes identified through analysis of written report. Themes compared with existing analysis, analysis updated.

Reflection and action meeting	Observation report and researcher's updated analysis sent to key staff and discussed at reflection and action meeting. Staff discussed and debated raw data and researchers analysis adding their views and rationales to determine meaning and understanding. Meeting notes typed and analysis updated and sent to key staff.
<p>Second interview with carer focusing on</p> <ol style="list-style-type: none"> <li>1. Their first interview</li> <li>2. Participant observation data</li> <li>3. Collective and cumulative analysis of case study data undertaken by researcher and key staff.</li> </ol>	<p>Interview recorded and typed up. Initial analysis conducted by researcher using Microsoft Word - key themes highlighted from text and analysis document updated. Interview sent to carer to check for accuracy, and consideration of any additional comments / thoughts. Carer contacted by phone to discuss this.</p> <p>.</p>
Reflection and action meeting	<p>Second interview with carer discussed and analysed with key staff from ward at reflection and action meeting. Researcher presented interview report and cumulative analysis and key staff debated themes in light of their knowledge and experience within the context of the ward.</p> <p>Researcher and key staff identified action points from cumulative analysis and determined a process of implementation and review. Meeting notes typed</p>

	incorporating discussion of analysis and sent to key staff, analysis document updated.
--	--

Figure 4 Data analysis processes

The purpose of this phased and continuous analysis was to adhere to principles of inclusion, democracy, and participation and to facilitate an analytical process that incorporated those people who had both local and in-depth knowledge of the phenomena under investigation. A further intended outcome of this process in regard to staff, was to increase awareness of pertinent issues (assessment and management of pain and distress and carer support for PWAD), enhance their ability to reflect and analyse information, and to generate a sense of commitment to action through deep understanding of these issues. This collaborative process was also vital in terms of the implications of data analysis upon consequent actions and changes to practice. The data process identified above incorporates both first and second person enquiry approaches. After each episode of data collection the researcher undertook first person enquiry then collaborative, second person data analysis and enquiry occurred for the reasons identified.

Key questions were used to direct the analysis of data: what have we found? What does this data mean? What, if any, implications arise from this data, for example in regard to individual care, processes of care, wider knowledge and understanding? What should be our response? How does this analysis contribute / support / contest theories relevant to this research such as person centred care and relationship centred care?

All data was analysed in written form. The researcher would argue that there was a definite need to be pragmatic and focus on key issues with participants. It was not appropriate to engage families and staff in analysing long verbatim transcripts of interviews, this could have been unwieldy in terms of the time taken to read and the ability to consider key issues / themes from a large mass

of data. The analysis had to focus on a new understanding of practice issues leading to change, not complete an in depth analysis for the sake of it. Participants had a range of abilities and experience and support was required to enable analytical discussions to take place, a natural nervousness was evident in participating in research, as participants were concerned about their abilities. The researcher had to carefully adopt a supportive, encouraging stance that facilitated participation. Acknowledging new ideas / concepts raised by participants was a useful strategy to encourage analysis and reaffirm the essential value of different perspectives in determining the validity of the work.

The researcher decided not to use a software package such as NVIVO but use a computer word package as this also allowed data to be stored and sorted according to developing themes. The researcher was concerned about working alongside participants and how they would cope with data presented from NVIVO, also the amount of data generated from the five sites participating in the parent project would have required a significant amount of time to apply to the NVIVO package and the benefits of this were unclear.

This chapter has described in detail the complexity of action research processes, specifically ethical issues, notions of participation and democracy, development of AR theory, first and second person enquiry, the necessity for reflexivity and issues of reliability and validity. As this is a multi method research process, justification for all data collection activities was provided. To provide evidence of data analysis, examples are included in Appendix 11.

The next phase of the research will describe the process of conducting a dementia palliative care needs assessment.



## **Chapter 4**

### **Dementia / palliative care needs assessment**

#### **4.1 Introduction to chapter**

This chapter will describe a research process that was initiated to meet the first aim of the research, namely: to identify the palliative care needs of people with a dementia and their carers in West Lothian. This chapter presents the first phase of the overall action research process and incorporates the following areas:

- Identification of the aims of the needs assessment,
- Definition of terms
- Inclusion criteria
- Recruitment, consent and confidentiality processes,
- Data collection methods,
- Analysis process
- Presentation of needs assessment priorities
- Utilisation of needs assessment priorities

It is necessary to clarify the purpose of conducting the needs assessment and the position of this needs assessment within the research process and the thesis as a whole. The needs assessment:

- Was chronologically the first research phase of the project and, as such, was a distinct process
- it was conducted to address the first aim of the research to identify the palliative care needs of people with a dementia and their carers in West Lothian;
- It was an essential starting point that would lead directly to the action research projects conducted with participating services that followed.
- The primary purpose of the needs assessment was to describe a situation from different perspectives to achieve an overview of needs across the local area of West Lothian. This would act as a driver for

change projects that would be initiated within local services that agreed to participate in the action phase.

- It was important that the local action projects to be initiated with West Lothian services reflected a broader strategic understanding of need rather than only focus on specific service development issues.
- It was essential that developments in practice were founded on evidence of need. This was particularly important when attempting to develop practice related to palliative dementia care. Dementia care is not routinely associated with palliative care; therefore there was scope for misunderstanding.
- To facilitate clarity about the phases of the overall action research, the needs assessment process would be presented as a distinct chapter.

An external driver initiating the conduct of a needs assessment was that NHS Lothian and social care services in West Lothian had requested that a needs assessment be conducted as part of West Lothian Dementia Palliative Care project. Similar assessments had been conducted in other areas of NHS Lothian and dementia care development work had been taken forward as a result. There was an acknowledgment that West Lothian needed to make progress in relation to dementia care and this needs assessment would provide a necessary basis of evidence to initiate developments.

As stated above, this chapter describes the needs assessment process in full. The chapter concludes with a section relating to the implications raised by the findings and the relationship between this needs assessment process and the rest of the action research.

As a result of the completed needs assessment process, six needs were identified as a priority. These six needs were;

1. Providing care that is person centred,
2. Managing pain and other symptoms for PWAD,
3. Supporting family carers,
4. The provision of respite care,

5. Equity of access to services and finally
6. The development of a strategic dementia group in West Lothian.

These six priorities were important as they provided a focus for the following action phases of the research.

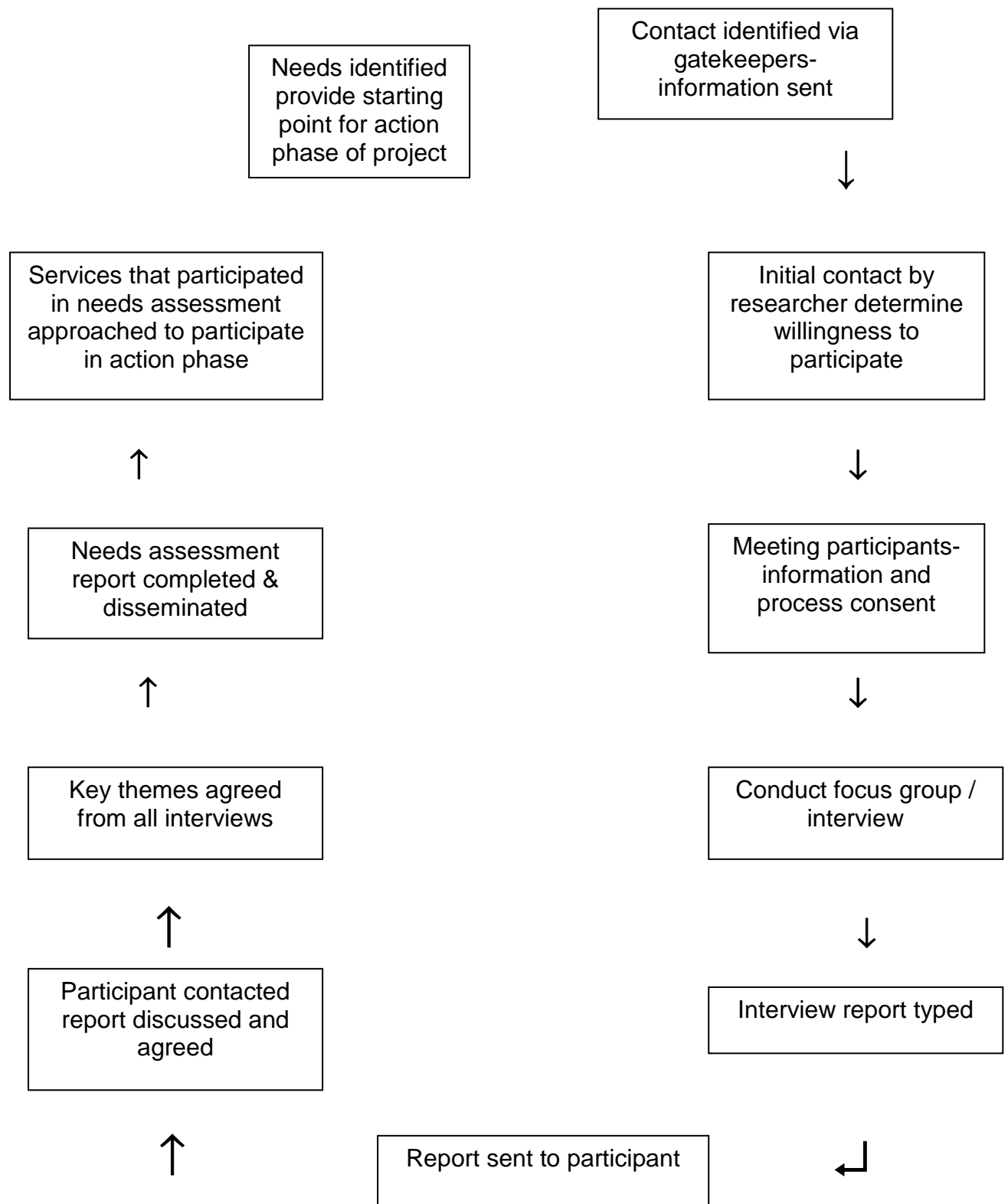
#### **4.2 Aims of conducting the needs assessment**

The needs assessment had a broad aim: to identify the palliative care needs of people with a dementia and their carers within West Lothian. There were however further aims in relation to the process of conducting the needs assessment, these are stated below.

- To identify the palliative care needs of people with a dementia and their carers within West Lothian.
- Needs to be identified by investigating the experiences and views of people with a dementia, carers and a range of service providers.
- The assessment will actively utilise methods which enable people with a dementia and their carers to participate.
- Ensure the action phase of the research, to be conducted after the needs assessment, is focused on evidence of local dementia palliative care need.
- Provide an information resource for PWAD and carers about services available in West Lothian.



**Figure 5**  
**Dementia Palliative Care Needs Assessment**



### **4.3 Definitions of terms used in the needs assessment process**

It is necessary, at the beginning of this process, to clarify the terms identified below. Palliative care and dementia care as two distinct terms, are open to interpretation and misunderstanding. In combination the opportunity for confusion is exaggerated, therefore clarity was needed from the onset of this process. This is specifically relevant as many would assume this needs assessment was about needs in the last days of life for a person with a dementia and not from the point of diagnosis onwards, Sachs et al (2004). Downs et al, (2006) identified that even within the focus of end of life care; different models of palliative dementia care may exist.

#### **Palliative care**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

(The World Health Organization, 2002)

A vital aspect of this needs assessment was that the approach regarded dementia conditions as palliative from the point of diagnosis onwards. There was not a specific focus on end of life or terminal care. It could be argued that this palliative care approach is synonymous with the general term dementia care, relating to any forms of care for PWAD and their carers.

#### **Dementia**

Dementia is the progressive loss of the powers of the brain. The most common cause is Alzheimer's disease. Other kinds of dementia are vascular dementias, alcohol related dementias, Lewy body dementia and Picks disease. What all these diseases have in common is that they damage and kill brain cells, so that the brain cannot work as well as it should.

(Alzheimer Scotland, Action on Dementia, 2006)

#### Mild dementia

Manifest impairment of attention and memory; forgetful of recent information; occasional confusion or disorientation; some help or guidance needed with any activities outside the daily routine (Roth et al, 1988).

#### Moderate dementia

Amnesia for recent events; some disorientation for time and place; severe impairment of reasoning and ability to understand events, resulting in dependency on others in personal care and routine daily tasks (Roth et al, 1988).

#### Severe dementia

Incoherent speech, disorientation for time, place and person; failure to recognise close relatives, incontinent of urine and faeces, complete dependence on others for basic personal care (Roth et al, 1988).

#### Respite Care

Within this process respite care is defined as a break from caring for the carer which may take place in a variety of settings, for example the person's own home, within a day care setting, within a care home or other in-patient setting. The person with dementia as well as the carer can receive benefit from these breaks in care, in the form of company from other people, stimulation, pursuing interests and getting out of their home environment.

### **4.4 Assumptions related to the conduct of the needs assessment process**

The conduct of this needs assessment was based on a number of assumptions. One of these was that people with a dementia and their families / friends, would be able to describe the existing services and support they receive and make conclusions about their needs, those which have been met or remain unmet. This process is an individual one therefore participants will base their views on their beliefs, values and previous experience. For example

participants who have had contact with few services may have little awareness of what is potentially available to them and state very few needs as a result of low awareness. It is recognised that users who participate may not represent other users of the service, their contribution is individual; they are not a homogeneous group (Peace, 1999).

The above issues are also pertinent to service providers as they describe needs of people with a dementia and their family carers. Additionally service providers may give a skewed focus of need in that they may have limited experience or a narrow perspective based on their own service experience. Cynically their contribution may be deliberately biased in order to positively influence change within their particular area of service rather than consider a broader, more altruistic perspective.

A further assumption made during this process was that involving PWAD, family carers and a range of service providers would result in a comprehensive understanding of needs. As a result of working with the above assumptions, the conduct of the needs assessment was a time consuming and labour intensive process. Carter and Beresford (2000) state there is no one best value form of older people's involvement, therefore there is no reason to promote uniformity, the approach needs to fit purpose. It could be argued that this statement has even more relevance to PWAD, as their abilities will vary, however the aim is to recognise their contribution and pursue sensitive involvement. This is particularly relevant as PWAD as a group amongst older people have previously been described as marginalized and overlooked (Carter and Beresford 2000, Higgs 2005).

The needs assessment also assumed that within these individual accounts of experiences and needs, commonalities could be identified through a process of analysis, which could then be acted upon and lead to service improvement.

Taking into consideration the above assumptions and challenges, this method of enquiry is an identified approach to establishing needs leading to the

development of policy, (Scottish Executive, 2005 Scottish Executive, 2006). The Scottish Executive document, Our National Health (2000), stated one of the objectives of the Health Service was to listen better, to patients and respond more effectively to their needs. It is both logical and reasonable that key stakeholders are involved in a process of identifying need and this is indeed preferable to service providers making exclusive decisions on behalf of service users. This has to be balanced however with tokenistic involvement of users, whereby they are included but their involvement is minimal and makes little impact on the overall outcome (Ansari et al 2001, Carter and Beresford 2000, Higgs 2005).

Due to the complexity of the subject, palliative care for PWAD, and the varied interpretations and assumptions that could be made in regard to this, a face-to-face approach using interviews and focus groups was utilised. This provided an opportunity for exploration and clarification of issues raised by participants. Due to this complexity, the sensitive nature of the subject and the potential for misinterpretation and assumptions, other approaches such as the use of questionnaires and surveys would have been difficult to utilise. As stated above there was also a desire to include PWAD and their carers in this process, the use of questionnaires and surveys would not have been appropriate.

#### **4.5 The purpose of a needs assessment**

It may appear obvious that a needs assessment is about establishing the needs of a particular group or community, however undertaking such work can have implications. Axford et al (2009) stated that conducting a needs assessment can be the result of a range of drivers; these can involve prioritising resources and requiring evidence to support decision making about resources, attempting to shape how services are provided and to identify baseline measurements whereby future measurement can evidence planned improvements or identify further unmet need. It would be concerning if the findings of a needs assessment did not result in actions or change as the process would have been triggered by concerns about the treatment or experiences of a particular group.

#### **4.6 How is a needs assessment conducted?**

Axford et al (2009) identified that there is little consensus as to what constitutes the process of conducting a needs assessment, methods vary significantly according to purpose and subject. Large scale studies involving quantitative approaches using questionnaires and population based representative sampling measures to small scale qualitative studies have been used and identified to be needs assessments. Other measures such as visiting relevant services and recording notes and reflections but also using information from services such as audit data and other service information about the numbers of clients who use the service were also identified as contributing useful data (Player et al, 2009). Boland et al (2008) in their conduct of a needs assessment, focussed on health promotion for people with a learning disability, identified triangulation of information as a positive approach. They used, for example, interview directed surveys, focus groups and postal questionnaires to a range of participants: people with a learning disability, carers and service providers. The groups of participants identified by Boland et al (2008) directly reflect the participants recruited, as part of this needs assessment about palliative dementia care.

Needs assessments require an understanding of context therefore data such as census information, demographic data, disease prevalence can be an essential starting place (Player, 2009). Within the context of this work, the rising numbers of PWAD in Scotland (Alzheimers Society, 2006) and the acknowledgement from professional and government bodies that dementia related diseases fall under a palliative care approach (Scottish Partnership for Palliative Care, 2006 Scottish Government, 2008) were key factors in providing a rationale to undertake this work.

The National Disability Authority (2002) identified inclusive methods for identifying needs, these included having a steering group to oversee the process and that membership should include clients, carers and service providers. This needs assessment adopted a similar approach however we did not have a person with a dementia on the group although we had several

carers, service providers and researchers. Other approaches can include using clients as researchers who can collect data. As identified previously there is a need to follow current strategic governmental approaches such as involving clients and service users, specifically focusing on consultation and involvement, (The Scottish Executive 2000, Scottish Government 2008). In regard to this needs assessment, involvement of PWAD and their carers at all stages of the process was a fundamental aim.

Finifter (2005) identified the components of a comprehensive needs assessment. These include a literature review, collection and analysis of consensus and archival data, surveys of community members and service providers and case studies to highlight specific practice / service issues. This needs assessment also utilised case studies to highlight and provide evidence for the key themes identified.

A further outcome of needs assessments can involve the creation of a directory of services that has not existed previously or has required updating. This primary outcome can, in itself, provide increased awareness of services for both service providers and the community / group being investigated (Axford et al, 2009).

#### **4.7 Limitations of needs assessment**

Little et al (2002) are critical of the overall process of conducting needs assessments. They state that a gap exists between the measurement of need and the subsequent actions taken. This needs assessment process was designed in such a way as to lead into direct action with services in the local area, therefore addressing Little's (2002) specific concerns.

Axford (2009) highlighted that needs assessments can be limited due to a lack of joint commissioning. Services conducting a needs assessment can focus on specific information in order to address their particular area of interest and as such limit the breadth and usefulness of the assessment. Joint commissioning of needs assessments is described as beneficial a range of organisations can

both direct the conduct of the work and utilise the findings. Within this needs assessment a range of services were involved in the steering group and consequently the planning and delivery of the assessment, however in retrospect social care services could have been more proactively involved initially as many of the findings involved a range of services including those provided by social care.

The limiting factors of conducting a needs assessment include the time available to complete the work, the size of the population under exploration, the ability of the population to participate in the investigation, for example being able to understand and communicate in data collection activities but also be physically able to take part. A further factor is the complexity of the phenomena under investigation. In respect of the conduct of this needs assessment the phenomena could be described as complex in that terminology and concepts of palliative dementia care were not widely acknowledged or understood by participants (Sachs et al, 2004) but also palliative dementia care is provided by an array of different services from health care, the voluntary sector, social care and specialist dementia care services. Understanding the communication links and inter working of these services, the aims and restrictions of each but also determining ways of enhancing palliation provided by these services to people with a dementia is complex and challenging (Hughes et al 2005).

Axford et al (2009) has identified further limiting factors in the conduct of needs assessments. These include the concept that identified needs are dependent on time and phases. A change in practice in one service or a new function or role can have a systematic impact on others and therefore results can change over time and in a phased manner. Axford et al (2009) are particularly critical of sampling procedures particularly in regard to large quantitative projects. Samples in this scenario should reflect, in some way, the population under investigation. These criticisms however can only be upheld when the overall process of the needs assessment is reviewed in terms of being fit for purpose, realistic and practically achievable.



In conclusion there is no one size fits all approach when considering the conduct of a needs assessment. Issues of gathering relevant evidence and information prior to data collection are important. Sample sizes and determining who participates are factors decided by both pragmatic and epistemological issues, pragmatic in terms of the length of time available to complete the assessment and epistemological in terms of the overall approach used to gather information, for example the use of positivist, deductive approaches involving sample sizes that reflect the population under investigation. The evidence points to considering issues of inclusivity when conducting the needs assessment and that outcomes should inform and change practice to some identifiable degree and not become redundant information.

#### **4.8 Recruitment of participants**

Three target populations were identified, these included people with a dementia, their family carers and service providers.

Ethical approval was sought and obtained from the Multi-Centre Research Ethics Committee for Scotland, in particular the committee responsible for research involving adults with incapacity. The committee requested minor changes to be made to the application, mainly in relation to the clarity of words used in patient information. As the ethics application identified the research to be action research, and as such all data collection could not be specifically identified at the onset of the work, it could have been anticipated that the ethics committee may have asked questions about this approach. This however was not the case and the application was straightforward.

##### **Gaining access to participants**

###### **Service providers:**

Service providers were identified via members of the project steering group and participants in the project. The aim was to involve participants from a broad spectrum of services and from a variety of disciplines. Inclusion of National Health Service, voluntary and social care services was sought. Service

providers included those who provided specific services for people with a dementia and generic services available to people with a wide range of needs including dementia care. Participants were sought from different levels of organisations including those providing direct care and those with managerial responsibility. Appendix 1 identifies services from whom representatives participated in the needs assessment.

Nominated individuals were initially contacted by phone and if in agreement an information letter was sent (see appendix 2 for information letter). They were then contacted a second time by phone and permission was sought to meet and conduct the needs assessment interview. Interviews were conducted in the participant's workplace. Consent forms were completed prior to conducting the interview.

People with a dementia and carers:

These groups of participants were identified via 'gate keepers' (Pratt and Wilkinson, 2002), that is service providers who were involved in the ongoing care of the person. Examples of gate keepers included community psychiatric nurses and staff from dementia day care settings. Inclusion criteria were outlined to these staff and if service users met these criteria an initial approach was made by the member of staff to discuss the project and outline what participation involved. An information letter outlining the study was also provided at this time. Following this initial discussion, agreement was sought for the researcher to make contact and discuss participation in more detail.

Due to the potential communication difficulties of working alongside people with a dementia it was identified that a flexible, supportive approach was required. This involved the researcher meeting people with a dementia to discuss participation in the project. This was in addition to discussions held with the gate keeper and the provision of the information letter. Similar arrangements to support people with a dementia were made available when the original interview was being reviewed. In practical terms this meant further contact, for example the interview report was read aloud by the researcher to the

participant and the content discussed during this process. It has been stated that this is the reality of involvement, adapting and responding to meet the needs of the individual to enable their participation (Barnes and Warren, 1999).

#### Issues of confidentiality

Names were removed from the final written reports. Participants were allocated a code and other potential identifiers were removed. The researcher was the only person with access to the names of participants. During the analysis of data one other person, a member of the project steering group, saw the anonymous reports. All data was securely stored within the researchers office and the computer used for this research was password protected and subject to NHS Lothian's confidentiality policies. The data will be kept for five years.

#### Inclusion Criteria for participants

##### People with a dementia

- People with a diagnosis of dementia confirmed by consultant psychiatrist
- In the opinion of the gatekeeper, able to understand the purpose of the interview and give informed consent.
- In the opinion of the gatekeeper, able to participate in an interview

##### Carers of people with a dementia

- A carer of a person with dementia
- The person with dementia has to have had their diagnosis confirmed by a consultant psychiatrist.
- The carer can be a relative or friend or neighbour
- In the view of the gate keeper known to the case, the carer provides a significant contribution to the care.

##### Service providers

- Representing a service provided in West Lothian
- Service may be either specific to dementia care or generic and include dementia care within a wider remit

- Provides a service for people with a dementia, carers or both

On the occasions when the researcher interviewed both the PWAD and the carer together both perspectives were considered and investigated. The interview questions for both participants follow the same sequence and focus. Pratt and Wilkinson (2002) identifies that there are both benefits and challenges to this approach. Benefits in that the PWAD has support and familiarity with someone they know and also someone to help them if they experience difficulty answering the interview questions. The challenges arise when one person dominates the interview, in this instance the likelihood is that the carer will speak over or for the PWAD. A further challenge relates to the existing relationship and ways of communication of the participants. Conducting this interview with both the PWAD and their carer had the potential to raise sensitive issues and difficult emotions, such as anger and guilt. One of the reasons for using gate keepers to identify and suggest potential participants, was their awareness of such potential dynamics and only involve people they felt are appropriate. To go 'blind' into an interview such as this, could raise potential problems and risks for participants. A negative aspect of this approach is that interviews are conducted with a selected group only and could not be described as representative of the group as a whole. As a consequence of this it is important to be transparent about participants and ensure readers of the research can make reasoned judgements.

#### Service information data:

Data was also collected about services available for PWAD and carers within West Lothian. The aims of collecting this type of data was to triangulate the data gathered from service users and providers, identifying gaps and needs within this geographical area. It is important to acknowledge that there is a raft of services available to people with dementia and carers, which are generic services available to anyone in West Lothian, for example, General Practitioners and District Nurses. There are also a wide range of services which people with a dementia and carers can be referred to, for example,

Speech and Language Therapists, Physiotherapists, Occupational Therapists, Dieticians, Psychologists to name a few. The service details included in the needs assessment report, concentrated on more specific dementia services or those generic services that had a specific remit for PWAD, for example social workers.

A further aim of gathering this data was to provide PWAD and carers with comprehensive information about services available to them in West Lothian. This information is not included in this thesis but was included in the report of the needs assessment. All participants received a copy of the needs assessment document and it was also put on the West Lothian Community Health and Care Partnership website as an information resource for people with a dementia and their carers. The services element of the needs assessment included information regarding referral processes and who to contact for advice. A specific example of this was information about who to contact when considering admission to a care home.

The researcher contacted services and asked for specific details about their service, the details included were as follows:

- The name of the service
- Contact details, address, phone number, website
- Name of the manager
- Hours of availability
- Brief description of the service

#### **4.9 Data collection methods**

Semi structured interviews or focus groups were conducted with participants. See appendices 3, 4, 5 for interview schedules. The researcher used the schedule in a flexible manner enabling the participant to discuss issues according to their particular emphasis. The purpose of this approach was to explore issues raised by participants with the use of open questions. It was

envisaged that questions might require varying degrees of explanation and support according to the individual participant's ability. Each interview / focus group was conducted by the researcher.

Prompt cards were used as a way of focusing on key aspects of palliative care, see appendix 6. These cards were developed in order to capture the definition of palliative care in a way that was practical rather than theoretical. It was recognised that the term, palliative care may be unfamiliar to participants and therefore presenting key words that give a brief explanation of terms could represent a user-friendly approach. The prompt cards also highlighted distinct components of the definition of palliative care. The aim was to facilitate consideration of key issues one at a time. A similar approach was adopted by Norman (2002), however instead of using key words, photographs and images were used as a means of prompting and engaging with the participant.

The interviewer took written notes throughout the interview. This is a challenging method of capturing data as it involves asking questions, actively listening and writing simultaneously. A particular challenge within this context, was communicating clearly and connecting with people who had varying degrees of difficulty interpreting and expressing information. In terms of depth of data analysis, a preferred approach would have been to audio record or video tape these interviews. The approach of recording data by writing responses during the interview was used for the following reasons:

- There were too many interviews to undertake audio recording, transcriptions and in-depth analysis, this would have been overwhelming in terms of time constraints. There was a preference to capture views from a range of people and services
- The data required for the needs assessment was not for the purpose of determining in-depth individual meaning for the participant, rather summarising their experiences and opinions with a view to determining a collective analysis of needs leading to service improvement.

- A checking process was in place for each participant to review the report written from their interview and make changes and or add additional comments. Efforts were made to ensure this was a real activity rather than a tokenistic approach to validity. A small number of participants, n=5 requested changes. These were related to specific details such as the wrong date or name on the report. No participants requested a change of meaning or interpretation of the interview report.
- The researcher actively reflected on the interview and data collection process, these reflections were shared with those who conducted an analysis of the data.

On completion of the interview the researcher wrote a report of the discussion and sent this back to the participant. The participant was asked to read the report with the aim of checking that it accurately reflected the discussion held. Participants were asked to change any inaccuracies and add any additional information that they considered relevant. The researcher then contacted the participants by phone or in person to discuss the report and make the necessary changes, participants agreed the content of the final report.

#### **4.10 Needs assessment data analysis process**

Data analysis initially involved the researcher and one member of the project steering group. This was to enable a robust analysis process where findings could be compared, debated and agreed. A latter stage of analysis involved all the members of the project steering group. The steering group member was a Nurse Manager, had significant clinical nursing experience of caring for people with a dementia and mental health services, had recently taken part in the development of a National Guideline for dementia care. They also had many years of personal experience of being a carer of a person with a dementia. The researcher and the steering group member met and agreed the analysis process detailed below. This meeting offered the opportunity to clarify and ensure understanding of the data analysis process. It was agreed that word computer packages would be sufficient to complete this process and a data

analysis computer programmes would not be used. This was agreed in regard to the time available to complete the process and the skills and experience of those participating. The researcher had completed training in software analysis packages but the steering group member had not had this opportunity and there was not time to undertake this form of training. With the amount of data to review and the knowledge and experience of the researcher and steering group member in this field, it was agreed that a word package would provide suitable support for the analysis process.

Each interview and focus group report was read and reviewed by the researcher and the steering group member independently. As each interview and focus group data was read, needs were identified. Analysis involved reading paper copies of the data and compiling a list of needs identified from each data source. Needs were initially documented in paper form and identified according to their data source. Once all data had been read and needs identified, the needs were analysed specifically. Needs were grouped together in that they had similar meaning or were in fact the same and had been expressed repeatedly in different data sources. Both the researcher and the steering group member did this stage of the analysis independently.

Needs were identified in two ways, from explicit statements of need included in the data but also from the experiences described. In these circumstances needs were inferred rather than explicitly stated by participants. Experience and knowledge about dementia care, local and national service provision and research evidence was essential for both the researcher and the steering group member. It could be argued that these requirements were met by both analysts and therefore an ability existed to make judgements about inferred needs identified from the data.

Following completion of the independent analysis, the researcher and steering group member met and discussed individual data, reviewing the process and outcomes of identifying need. These discussions provided an opportunity for the reviewers to debate and compare those needs inferred by the experiences



of participants as well as those explicitly stated in the interview / focus group reports.

Following this process both analysts reviewed their theming of the needs from individual data sources. This gave the opportunity to debate and agree the overarching themes that emerged from the data and discuss the relationships between the identified needs and emergent themes. Following this analysis work the researcher and steering group member returned to the original data and identified evidence (quotes and case studies) that acted as a clear exemplar for each theme and sub theme. The purpose of this particular stage of the analysis was to clarify the needs identified in respect of real experience and evidence and to clearly demonstrate this to those who would read the report and have access to the findings, PWAD, carers and service providers.

This combined analysis, conducted by the researcher and the steering group member, was then reviewed for a final time by members of West Lothian Dementia / Palliative Care Project Steering Group (Appendix 7 outlines the membership of this group). The group reviewed the analysis for two reasons; first to determine that the analysis of needs was logical in terms of the themes developed and that the inclusion of relevant quotes and case study examples accurately reflected theme development. This process aimed to provide clarity by challenging the themes developed, ensuring duplication was avoided, and that language used to define needs was clear, also that no key themes had been overlooked. The steering group had a wide range of experience and knowledge including those who were actively caring for PWAD. This process drew on their collective expertise. Secondly the group also made a collective decision in terms of identifying priorities from the results and analysis of the needs assessment data by agreeing key messages. The needs assessment had purposely been conducted as a trigger for the development and co-ordination of dementia care services, therefore it was necessary to produce a concise report that could easily direct service providers to areas of need.

#### **4.11 Participation in the Needs Assessment**

The needs assessment was conducted between March and November 2004, a period of nine months.

In total there were 96 participants, (8 people with dementia, 25 carers and 63 service providers).

Appendices 8, 9 and 10 outline information regarding participants from the three groups: people with a dementia, carers and service providers respectively.

#### **4.12 Priorities from the Needs Assessment**

This section will identify the six priorities identified from analysis of the needs assessment data. Data in the form of case studies and quotes from participants will be presented in order to highlight these needs.

The rationale for identifying priorities from the needs assessment were twofold. First to consider the key issues to address, in terms of the action research project to follow. Second to highlight key needs to those with responsibilities for managing services in west Lothian, in particular managers from the Community Health and Care Partnership.

Analysis of data identified the following six priorities:

1. Provision of person centred care
2. Management of pain and other symptoms
3. Carer support
4. Provision of respite care
5. Equity of access
6. Development of a strategic group with responsibilities for dementia care in West Lothian

## 1. Provision of person centred care

*I know him really well so I can pick up when things are wrong,'*  
(a family carer).

*I know when she's sore by the way she moves, asking her questions doesn't work,'* (a family carer).

*'He feels worthless, he is always putting himself down. We are constantly saying to him you are still you despite your problems, he needs such a lot of reassurance. The issues of being unable to drive and work have had a huge effect on him.'* (a family carer)

These quotes above highlight the importance of knowing the person with a dementia and the consequent challenges that exists for service providers who have a responsibility to get to know and understand the person in order to care for them in a person centred way. The second quote particularly focuses on a family carer's intuitive understanding of behaviour and its meaning in regard to experiencing pain.

*'Its important to encourage staff to see clients in an individual, holistic way and address problems using this approach...How would you like one of your family to be treated / spoken to if they had dementia?'*  
(Service provider)

The above comment from a service provider highlights the challenge of treating people in an individual way, particularly when PWAD are cared for in a group setting for example in a hospital ward or care home. In these settings compromises can be necessary as the needs of many can impact on the desire to provide individualised care. The service provider in this instance, adopts a challenge for their staff encouraging them to think of PWAD as people, such as those in their family and as a result how would they want their own family to be cared for and spoken to.

It is concerning that in 2004 a prioritised need in caring for PWAD continues to focus on the provision of person centred care. This would indicate that the laudable and acclaimed personhood theories of Tom Kitwood in 1997, as discussed in the literature review chapter, have not been realised within a practical sense within care settings for PWAD within West Lothian.

## 2. Management of Pain and Other Symptoms

*'She had a really bad time in the ward; she had pneumonia and suffered a bit of pain with her arthritis. It took a long time to get on top of the arthritis pain.'*  
(Family carer)

The quote above was taken from an interview with a carer however this particular episode of care was also highlighted by a member of staff. This case study will be presented in some detail as it highlights an important care issue. When the problem of pain is not recognised it can have significant implications and result in severe distress not only for the PWAD but also their family member. This situation also poses challenges for staff as they attempt to provide care and address the needs of the patient. The following case study provides further details related to the family carer quote stated above.

### Case Study

This particular carer's experience was traumatic. His wife had been admitted to hospital as she had developed pneumonia and this had exacerbated her dementia problems. Whilst in hospital his wife deteriorated and her behavioural problems became severe and distressing. She would scream and tear her bed sheets with her teeth but also during episodes of care she would bite the nursing staff. This behaviour was significantly different to anything her husband had witnessed before. Her husband became very distressed by this behaviour, concerned for his wife and her obvious distress but also humiliated and concerned for the staff, feeling guilty about the problems she was causing on the ward. During his interview he described visiting his wife as traumatic, worrying what she had done and which nurse she had bitten.

After a period of many weeks a nurse visiting the ward asked whether the lady could be in pain. The staff investigated this and it became apparent that the analgesia she had taken for a number of years for severe arthritic pain had not been prescribed for her since admission to hospital. The admitting hospital doctor had omitted to identify this information and no one else had identified

the problem. The carer had assumed that she would be receiving her usual medication and didn't think to question this aspect of her care, he was also unaware that this significant behavioural change could be associated with pain, along with the staff, he had assumed it was related to her pneumonia and dementia. Analgesia was commenced and the lady, over time, responded to this and her behavioural problems resolved markedly.

The importance of this scenario is that it is representative of key problems in regard to pain care for PWAD that arose during data collection and is identified in research. Key problems such as a lack of understanding of a person's previous problems with pain, a failure to actively engage a carer in developing an understanding of the needs of the PWAD, assuming behaviour is solely related to dementia, not investigating causes of distress particularly not actively adopting a problem solving multi disciplinary approach and finally missing the connection between pain and behavioural change for PWAD who have difficulty communicating. There is a real challenge for nurses to be constantly vigilant and responsive to the potential problem of pain for people who have a dementia and who have difficulty with verbal communication.

*'Its difficult to assess, she would deny being sore if you asked her. I am impressed at the nurses though, they had a dentist come and look at her mouth as they thought her mouth was sore due to a cavity.'* (Comment from carer)

A body of literature exists, which collectively highlights undetected and untreated pain for people who have a dementia and recognises pain assessment as a significant clinical challenge (Morrison and Sui, 2000 Weiner et al, 1999 Lefebvre-Chapiro,2001 Krulewitch et al, 2000 Kovach et al, 2002). A number of pain assessment tools are available for nurses, which have gone through various levels of research. The tools most commonly referred to for people with a dementia are the Abbey Pain Scale (Abbey et al, 2002) and the Doloplus II (Lefebvre-Chapiro, 2001). A tool that identifies whether a person is experiencing distress and ways of identifying potential causes, is the Disability Distress Assessment Tool (Regnard et al, 2006). A significant feature of these tools is the observation of behaviour as a means of identifying pain or distress.

Despite a research focus on this subject there remains a need to enhance practice and achieve better patient outcomes of care in this area.

### 3. Carer Support

*'In terms of support, the social worker and the community psychiatric nurse have been very helpful. If the current support was not in place she would be in a nursing home,'* (comment from a carer).

*'It does help to talk about it, it's wrong to avoid contact. The loss is very difficult. I find the carers meeting very enjoyable, its good to talk with others and to hear what is going on.'* (comment from a carer)

*'The news was devastating; I had to take a week off from work just to get my head round it. I felt we had to push for information, to find out what the actual problem was. After we got the diagnosis we spent a lot of time on the internet trying to find information about Alzheimer's. We would say we were very much left to our own devices, there didn't seem to be a plan in place to help us.'*  
(Comment from a carer)

The above quotes from family carers emphasises the importance of support. In this instance the carer felt that support had enabled their family member to remain at home. This is an important issue as home can represent a stable and positive environment for PWAD. The challenge however is to support carers appropriately enabling them to provide care at home for as long as possible.

This needs assessment highlighted a definite need for service providers to be aware of and act upon the difficult situations experienced by family carers of people who have a dementia. This is consistent with literature that identifies multiple challenges for family carers. The Health Education Board for Scotland (2003) identified guidance for a wide range of issues for family carers. These include developing a knowledge and understanding of dementia itself, learning to cope with their caring role, financial and legal issues, the practical issues of providing daily care, identifying where help can be sought and in the latter stages, issues related to admission to a care home.

*'Its important to acknowledge feelings of grief, guilt and anger and the variation of coping strategies carers adopt,'* (Service provider).

*'A three-pronged approach of support is useful for carers; 1) education and information from professionals, 2) ongoing professional support, 3) mutual support from other carers,' (Service provider).*

These quotes emphasise that caring, like dementia itself, impacts on people in different ways. Service providers need to be aware of this and respond to the individual needs of carers. The second quote, from a very experienced dementia care provider, stated that a combination of strategies can be a useful approach to supporting carers.

It is important to recognise that families can care for their relative for years, in some instances up to 10 years. For those families who take on a caring role the difficulties and stresses are well documented. 'The manifestations of dementia often cause great physical, emotional and social strain on the lives of family caregivers', (Maas et al, 2004). Brodaty et al (2003) highlights that those family carers of PWAD, experience higher levels of depression and poorer physical health compared to control groups of people who do not provide care.

Annerstedt et al, (2000) identified the prediction of breaking points, when family carers can no longer cope with their caring role. These include when the person with a dementia has an impaired sense of identity of the caregiver or misidentifies them, when the time spent caring is substantial, when the person has clinical fluctuations and when there are problems at night and the carer's sleep is disturbed.

Within literature a number of interventions have been identified and used to help family carers look after people with a dementia at home. These include education and training programmes, support groups, counselling and breaks from caring (Brodaty et al, 2003).

The needs assessment reinforced the need for a range of services to be available to support carers and indeed emphasised the importance and need for carer support. The range of services available to support family carers was

deemed to be limited and this is emphasised in the next priority from the needs assessment, namely the provision of respite care.

#### 4. Provision of Respite Care

*'Supportive care can be rigid and not meet the needs of individuals, more flexible care would be useful, specifically the time it is available and the flexibility of associated transport options,'*  
(Service provider)

*'You do get to a certain stage when you need more help and this is for her benefit. It can be difficult to get help that fits in with the time she wants to do things, for example she gets help at bedtime but she refuses to go to bed and it is not until it is really late that she gets to bed.'* (Comment from a carer)

*'She attempted to go to a day centre but this was unsuccessful as she changed her mind and didn't want to go. I felt this was due to embarrassment and some anxiety as to how she would cope.'* (Comment from carer)

The needs identified in regard to respite care were: flexibility, increased provision of services and for the availability of a variety of models of respite to meet individual need.

*'I would take my wife out shopping in the car and then use a wheelchair...she would always be keen to get out of the house, but when we were out she would want back. She would start shouting and trying to get people to help her, it was very difficult. Ultimately I needed my daughter to be in the car with her as she would try and get out whilst I was driving.'*  
(Carer)

*'It would be really helpful if someone could sit with her and let me go out or let me get on with ordinary things.'*  
(Carer)

The following case study provides further information related to the carer quotes stated above, and highlights the consequences of providing continuous care.

Case study
The needs above appear straightforward and logical, however the experiences of this carer were extreme in that his wife became distressed if he left her side or wasn't sitting next to her holding her hand. It is impossible to understand the



cumulative impact of this intense form of caring. He described only being able to have a shower very late at night when his wife was sleeping. If he left her whilst awake she would scream shouting out his name and become very tearful and distressed. As the quote above highlights, he became unable to take her out due to the distress and risks involved, and when eventually he got 2 hours of respite care a week, he spent this time at his local supermarket shopping. This caring role resulted in a reliance on alcohol and depression and significant feelings of guilt when he could no longer sustain this degree of caring. He then had to experience the trauma of leaving his wife within an in-patient setting and instigate a forced separation out of necessity as he could no longer cope with the caring role. The respite provision this carer received was inadequate in that it was too brief, initiated too late and offered little flexibility.

The experiences outlined in the above case study are important to highlight as they emphasise the enormity of the impact of caring for a PWAD. These experiences impact on the carer's physical, psychological, social and spiritual wellbeing. In the above case study the carer identified a dependence on alcohol and experiencing depression as a direct result of his caring role.

In terms of positive experiences of respite, this occurred when local community links were kept alive, these had a positive impact and provided a form of respite which was mutually beneficial to the PWAD and the carer. The abstract below provides an example of this.

*'She attends church once a month which is organised for elderly people, she gets picked up for this. This is something she looks forward to and takes great benefit from.'*

(Carer)

During the conduct of the needs assessment, respite care linked to providing carer support was a need identified by participants. These needs have also been identified by the Scottish Executive, (2005). They reported that the following actions would most usefully address the needs of carers:

- Giving unpaid carers a right to regular breaks from caring and providing more and better quality respite options

- Increasing the benefits of people with support needs
- Offering cash payments rather than services so that unpaid carers can arrange care according to needs and preferences
- A greater emphasis on information and training, advocacy and guidance including emotional support.

## 5. Equity of Access

The need to identify equity of access was highlighted by a number of experiences identified during the needs assessment. For example people with early onset dementia have a need for services to be available but they have specific needs. One carer highlighted issues related to equity of the provision of respite care.

*'Getting respite places is hard, there aren't places for his age group so there are a lot of restrictions.'*  
(Carer)

A familiar scenario linked to this need, was when a younger person was provided respite care within a service provided for older clients. The activities and ethos of the service were focused on older people and it was difficult for the service to adapt to someone with different needs. Carers identified that this situation also impacts on them as they feel a greater sense of guilt about leaving their family member in a place that is not suitable and where there is an expectation that the PWAD will derive little benefit from this period of care.

*'People with early onset dementia have unique and complex needs, there is a definite lack of resources for this group.'*  
(Service provider)

This comment related to the broader issue of a need for a range of appropriate services. An example of positive practice was provided by Alzheimer Scotland. They provide a beneficial service for younger people where a be-friender works with the client on an individual basis. They do ordinary activities together but importantly it is focused on the needs of the client and is flexible, they can be at home or go out to the pictures or pursue other activities. The difficulty around

this service is its funding. A limited budget is attached to this from West Lothian Council, the consequence of this is that few people receive the service and it is usually limited to once a week.

This service was highly valued by those who received it as it addressed many key dementia care issues. The service provided an individualised approach, continuity of care, someone who knows the person and their family well, flexibility and a focus on the person. The needs assessment flagged up this service as an important model of care, potentially not only for those with early onset dementia.

In regard to the subject of dementia medication, the following comment was stated by a person with a dementia.

*'We waited a long time to start the medication and this caused us a lot of anxiety as we felt time was moving on and we weren't getting any treatment. We were really anxious that treatment would start as soon as possible.'*  
(Person with a dementia)

This is a particularly difficult issue for PWAD and their families, and at the time of writing this needs assessment there was disparity regarding the provision of equitable treatment across the United Kingdom (SIGN 2006, Boyle 2005). The National Institute for Clinical Excellence in England decided that the drug is not cost effective and therefore should not be prescribed.

## 6. Strategic Group with Responsibilities for Dementia Care

*'Health, social care and agencies need one another in order to provide comprehensive care for people who have dementia and their carers.'*  
(Service provider)

The assessment identified a number of palliative / dementia care needs in West Lothian. Many of these needs relate to the organisation, provision and development of dementia care which were over and above the remit of this research and are the responsibility of a variety of services and agencies in West Lothian. In order to capture and take forward these elements of dementia

care, and to act as a strategic focus, the Project Steering Group identified the potential for a partnership, multi- agency group who would have the ability to focus on dementia care issues and develop strategic ways of working in West Lothian. This co-ordinated, multi agency approach may provide the optimal situation to facilitate the enhancement and development of dementia care within this area.

A number of the needs identified were related to services working together, in order to provide a useful, co-ordinated approach for PWAD and carers. Issues such as having a key contact, enhanced collaborative working between palliative care and dementia services, partnership working (voluntary sector, health and social care) and greater flexibility of services for people with dementia and carers were not issues services could address in isolation, a co-ordinating strategic body was required to review and manage the overall situation. Through the needs assessment process it was evident that there was no such co-ordinating body within West Lothian and that dementia care had fallen under the broader remit of older people, however in reality this had not been addressed in a co-ordinated strategic manner. In view of the rising numbers of older people and consequently increased projected numbers of PWAD, it was agreed that this was a necessary sixth priority. This is entirely in keeping with key initiatives from the Scottish Executive. They have provided a means to working in a strategic, co-ordinated manner to enhance dementia care across services by producing their template for dementia services document (Scottish Executive, 2004).

The broader Project Steering Group aimed to highlight this gap in strategic dementia care development to those with responsibility in the West Lothian Community Health and Care Partnership. This newly formed organisation had, as its core business, a responsibility to work across organisational boundaries to enhance social and healthcare services.

#### **4.12 Implications following the needs assessment**

The critical outcome of the needs assessment was that it provided local and current information about palliative dementia care in West Lothian. It is reasonable to state that the needs identified had previously been identified in literature, however it was important that priorities were evident and they particularly related to the local area.

The assessment was positively recognised by local services in that the process had directly engaged with people with a dementia, carers and a wide range of service providers. Engagement with PWAD and carers had been active and aimed to be flexible and supportive, enabling participation.

In the months following completion of the needs assessment, members of the Project Steering Group met with managers from the West Lothian Community Health and Care Partnership to discuss the needs assessment outcomes and consider ways to progress this work. After a period of many months a strategy group was established with the aim of developing a strategy for older people and people with disabilities. A sub group of this main strategy group was also formed with the aim of developing a West Lothian strategy for people with dementia and a key document utilised by this group was the needs assessment. It can be argued that it took local information, collected in a systematic way to influence developments in West Lothian, particularly the development of a strategic group. There were other factors that enabled this process to take place and these will be described in the following chapters.

The six priorities identified in the needs assessment would form the basis of the following phases of the action research. As stated previously the six priorities were:

1. Providing care that is person centred,
2. Managing pain and other symptoms for PWAD,
3. Supporting family carers,
4. The provision of respite care,
5. Equity of access to services and finally
6. The development of a strategic dementia group in West Lothian.

This would ensure that developments in care were responsive to needs based on local West Lothian evidence and not only the ideas of individual participating services. The action research focus would have to combine local service needs and the broader evidence, identified in this process.

The conduct of this needs assessment emphasised both the benefits and the challenges of involving people with a dementia and carers in a research process. Challenges involved being flexible and adopting approaches that met individual needs. An example being giving time and meeting participants ahead of data collection to describe and engage them in the process whilst meeting the researcher. This experience had positively reinforced the need to involve people with a dementia, as they were able to actively contribute to the process and express their views. This principle of involvement would continue to the next phases of the research where participation and collaboration would take place with PWAD, carers and service providers.

The local information this needs assessment provided enabled the second phase of this research to address real practice issues regarding the palliative care of PWAD. It also highlighted that despite issues such as person centred care being well known within dementia care and reviewed in literature, gaps in the ability to practically provide this care existed and required addressing. This provided an impetus and focus for phase two of the research.

## **Developing a baseline understanding of participating services and understanding their beliefs and values**

### **5.1 Introduction to chapter**

This chapter will describe a phase of the action research where the researcher began to work with participating services, with a view to understanding the aims of their service, and how it was provided. This activity was a necessary precursor to identifying and introducing a change to practice, as it enabled a realist appreciation of the service and staff. Data collection methods and findings will be described along with a collaborative feedback and analysis process undertaken between the researcher, staff and volunteers. The chapter will conclude with a description of the agreed focus to be taken in the next action phase of the research and the researchers' reflections regarding this process of developing a baseline understanding of Meadow Day Centre and Almond Ward.

Following this, commencing in section 5.11, a phase of the research will be described where staff and volunteers from participating services were engaged in focus groups to determine their beliefs and values about supporting family carers of PWAD (Meadow Day Centre) and the assessment and management of pain for PWAD (Almond Ward). There will be an introduction stating why this form of data collection took place and its relevance in the cyclical phases of this action research. The aims of conducting beliefs and values focus groups will be outlined as will the development of the questions used. The facilitation and participation of the groups will be described and finally findings will be identified along with their implications for the remainder of the research.

### **5.2 Aims of developing a baseline understanding of participating services**

Coghlan and Brannick (2005) state the need to 'have a breadth of pre-understanding in order to determine the context of the action research setting.' They argue that there is a need to have a comprehensive understanding of the

organisation, the environment, how the organisation undertakes its work and what it claims to be its aims. Data collected, which enables this level of understanding, has to be rigorous but relative to a particular need. In this research the overall objective related to the palliative care of people with dementia, therefore this particular focus required an understanding of the needs of people with dementia and their carers and how the service addressed these. It will also be necessary to measure the quality of care currently provided. This can enable an understanding of what is positive in the delivery of the care and what elements could be enhanced. To perform such an evaluation it will be important to understand the processes of care practiced, namely how people are assessed, how care is planned and delivered, and to what extent PWAD and their carers are involved in this. An understanding of the working ethos of each participating service is needed in order to facilitate a relevant, realistic working relationship between the researcher and staff, with a view to planning any action or change to the way care is delivered.

To summarise, the aims of collecting baseline data from the participating services were to:

- Enable the researcher to develop a pre- understanding of each service; namely who uses the service, its aims, who provides it and both positive and challenging aspects of providing the service.
- Identify the perspectives of staff and family carers in regard to the service, in particular the quality of the service.
- Establish positive working relationships with key personnel from each service.
- In preparation for the following action phase of the research, develop an understanding of the service's ability to make changes and develop their practice.
- Identify the dementia palliative care issues to be developed during the action phase of the research to follow.



### **5.3 Selection of services to participate in the action phase of the West Lothian Dementia Palliative Care Project**

Following completion of the needs assessment work presented in chapter three, a process of identifying and recruiting services to participate in the action phase of the research was undertaken. The responsibility for this process lay with the West Lothian Dementia Palliative Care Project Steering Group (membership of this group is identified in appendix 7).

The steering group decided to involve five services in the action phase of the project. This number was identified by the steering group; consideration was given to working with as many services as possible in order to achieve maximum project impact, but to avoid diluting the work by over stretching resources. Other inclusion criteria were that participating services should be identified from both health and social care services. This was in recognition of the development of a joint health and social care service in West Lothian (West Lothian Community Health and Care Partnership). A further factor given consideration by the steering group was to directly engage with services that had participated in the needs assessment process, and who had expressed a particular interest and enthusiasm to participate in the action phase of the project. Positively selecting interested and enthusiastic services was a deliberate strategy. The subject area, palliative care for people with a dementia was complex, furthermore there was a need to actively identify and change an aspect of practice, and therefore an explicit positive selection process was agreed and implemented.

The final inclusion criteria considered was to actively represent services that PWAD and their carers would make contact with throughout their dementia experience. This was in keeping with the broad perspective of palliative dementia care adopted by the research, namely that the approach regarded dementia conditions as palliative from the point of diagnosis onwards. There was not a deliberate focus on end of life care. It could be argued that this

palliative care approach is synonymous with the general term dementia care, relating to any forms of care for PWAD and their carers.

The five services that met the inclusion criteria described above and participated in the project were:

- Two day centres (one was a specialist centre for PWAD, the other was a day centre for older people which included a small number of PWAD)
- A hospital assessment ward for older people with mental health problems (patients had a range of problems, not solely dementia related illnesses),
- A specialist dementia continuing care ward in a community hospital
- A ward in a care home providing continuing care for PWAD

#### **5.4 Justification for selection of services to include in doctoral research**

The recruitment of five services, described above, to the West Lothian Dementia Palliative Care Project resulted in a very large and complex action phase of the project. The complexity and breadth of the whole project presented a significant challenge in terms of the depth of analysis required for this doctoral thesis. An element that further added to this challenge is the importance of context in action research. As described above in section 5.2, an understanding of the research context is necessary to make sense of the action research process, particularly an understanding and analysis of the change processes that occur.

In order to achieve a depth of analysis and coherently present this throughout the thesis, this thesis will focus on two of the five services that participated in the broader project. This would negate the difficulty of understanding analysis in respect of five different services that had distinct cultures, environments and service provision.

On what basis were the two services to be included in the thesis selected? The inclusion criteria detailed in section 5.3 also applied to the selection process for

the two services included in this thesis. This meant that the two services selected for the doctoral thesis would mirror the inclusion criteria and be representative of the work of the broader project.

A factor in deciding which two services to include in the thesis was a desire to represent the distinct foci of the action phase of the project: namely the assessment and management of pain and distress for PWAD; and supporting family carers of PWAD. A further factor was to be consistent with the model of palliative care adopted for this study, namely that palliative care for PWAD and their family carers begins from the point of diagnosis until death. A positive selection that would take cognisance of this model would involve a service used in the earlier phases of the disease when the PWAD was based at home and one where the person was provided care towards the end of their life.

Other factors were the potential to select a service that represented a health service and a social care service; this would ensure that the thesis would include services that represented two key organisations that are providers of dementia care and would be likely to have different cultural norms and ways of working.

A further factor to consider was the possibility of selecting a specialist service for people with a dementia and a non-specialist service. This would provide insights into the challenges and benefits experienced by both services when trying to enhance practice.

The five services that participated in the project were broadly split between day care services and in-patient services; therefore a further consideration was the possibility of having representation from both.

Taking these factors into consideration, the two services selected were Meadow Day Centre and Almond Ward, pseudonyms have been used to provide anonymity. The rationale for the selection of these two services was agreed at meetings of the research supervisory team.

Meadow Day Centre was selected as it represented a day care service provided under the auspices of social care services. Clients were most likely to be at the moderate stage of dementia and lived at home. The day centre was a non-specialist dementia centre, working with older people who had a variety of needs, not only clients with a dementia. The staff from the centre had chosen to focus on supporting carers of PWAD as part of the action phase of the project.

Almond Ward was selected as it represented an in-patient unit provided by the National Health Service. It is a continuing care specialist dementia service specifically for women who have a dementia. Patients who use this service have severe dementia and would be cared for towards the end of their lives. The staff from Almond Ward chose to focus on the assessment and management of pain and distress for PWAD.

It could be argued that the above two services represented particularly successful involvement in the research process, hence their inclusion in this doctoral thesis, a form of cherry picking. In reality each of the five services that participated in the broader project could have been selected and presented in this thesis. Each service initiated a number of practice changes in respect of their chosen focus of palliative dementia care and the author would argue that learning and practice development occurred in each of these settings. Similarly all services had their unique challenges and limitations, which would have been worthy of description and analysis and therefore inclusion in the thesis.

## **5.5 Methods for collecting baseline data**

Appendix 13 identifies the information that was gathered as part of the collection of baseline data. Information regarding the rationale for collecting this information and the data collection methods are also identified within this appendix.

The approach used in this baseline understanding phase adopted a multiple data collection approach. The following data collection methods were used to collect baseline data; participant observation, review of various service documents and policies such as complaints and assessment procedures , interviews with staff and carers, completion of the Revised Elderly Persons Disability Scale (Flemming, 1994) and recording field notes and reflections. Participants in this process included staff and volunteers and family carers. Clients were involved in participant observation but not directly involved in interviews at this stage of the research.

## **5.6 Baseline understanding of Meadow Day Centre**

In order to summarise and highlight key findings from the baseline data gathering a pen portrait of Meadow Day Centre is included below.

Appendix 14 provides a summary of the baseline data collected from Meadow Day Centre.

### **Meadow Day Centre: A pen portrait**

The day centre operates as a community centre, multiple activities such as clubs take place there as well as day centre activities for older people. As part of these day centre activities, care is provided for a small group of PWAD, around six to eight attend. The main purpose of the day centre is to provide a place to socialise, have lunch and take part in activities, such as dominoes and craft work. Many of those who attend experience isolation due to bereavements and lack of contact with family and friends. These aims also apply to those clients who have a dementia although an additional purpose is to provide

respite for family carers. The centre tries to foster close relationships with its community, making links with local services such as local food co-operatives.

The centre offers a flexible environment for a day care setting. There is a room which is used for PWAD, it is furnished in an old fashioned manner and is equipped with resources for this group. The centre has a sheltered central garden which most of the rooms look on to. This provides a further resource and space that can be used. The décor is bright and staff actively keep the appearance of the building smart. In terms of décor and facilities for PWAD, a number of key issues have not been considered, for example signage, floor and wall coverings. These can cause problems of disorientation and trigger visual misperceptions for PWAD. There was evidence of some dementia friendly environmental awareness in that they had installed coloured toilet seats, acknowledged as good practice.

Staffing within the unit is small and stable, there are always volunteers who work at the centre and those on placements such as Community Service. The volunteers provide a significant contribution to the daily working of the centre however their abilities and training are variable and there can be challenges regarding the appropriateness of these placements. One of the care workers has the responsibility for providing support for PWAD. He is enthusiastic and has developed knowledge and skills in relation to this, however this is not a shared responsibility. In a broader sense all the staff muck in together, there was little sense of hierarchy.

The dementia care support worker provided evidence of an ability to identify a problem, source information and make changes to practice that were felt to be useful. The centre has the autonomy to make changes to their practice as necessary. At the time of undertaking this work the centre did not come under the jurisdiction of the Care Commission however this changed as the research continued.

The centre receives funding from West Lothian Council, raises money as a registered charity and clients pay for their day care and lunch. There was evidence of financial constraints. The centre is subject to quality monitoring by West Lothian Council and there is a management committee who have overall responsibility for the running of the centre.

A range of health and social care staff refer clients to the centre, self-referral is also possible. It is unusual to receive comprehensive information in a referral and when a person is discharged it is unusual to share information with another service. Contact and links with other professionals / services is limited and ad hoc and it can be difficult to contribute to multi-disciplinary discussions. The management committee of the centre has strong links within social care services in West Lothian.

PWAD are assessed regularly and a dependency score is calculated. There are no care plans for clients. There appeared a lack of focus once the initial assessment had been completed. Clients were given choices and encouraged to pursue their interests, this was negotiated with them.

Families have limited involvement whilst clients attend the day centre. There was a strong philosophy about protecting families of PWAD. The manager had recent personal negative experiences of being a carer and had proactively taken steps to ensure staff were aware of these and that their service would learn from them.

Meadow Day Centre's REPDS facility profile shows relatively low percentage disability scores across the seven domains. The reasons for this are that all clients were included in the profile, not only the smaller sub group of people with a dementia who attend the centre. In order to attend, clients have to be predominantly independent in personal care. The highest disability scores related to self-help skills and sociability, it is evident the group of people with a dementia will have influenced these scores as well as other people who experience isolation that attend.

(Details found in appendix 14).

### **5.7 Feedback of baseline information at Meadow Day Centre**

Information was fed back to staff at various times during the baseline data gathering. This took the form of sharing observations with them and asking clarifying questions. Once all information had been gathered a meeting was held with Jean the manager and Tam the dementia support worker. They were provided with the report ahead of the meeting and we discussed the information. In reflective notes taken from the meeting, the informal, non-hierarchical and open nature of our discussions was noted.

In respect of the findings specified above, broad issues became evident through our discussion. There is a focus on the individual, giving choice and respecting autonomy; this applies to both clients and carers. The day centre, in keeping with a social care perspective, has strong links with the community and has a multipurpose function, therefore providing dementia care is only one aspect of the work. The centre's facilities were positive in terms of space and resources and access to a beautiful garden.

There was evidence of trying out different ways of providing their service, this was positive in terms of staff identifying a need and taking forward development. A challenge identified regarding these developments however was the lack of connections with other services, the baseline data highlighted that they made changes quickly with minimal consultation with their service users.

There is a stable staff group but responsibility for dementia care predominantly falls to Tam. A need for greater understanding and awareness amongst all the staff regarding dementia care was expressed. Volunteers from New Deal and Community Service placements caused concern as they had little awareness and insight into the service, coupled with a lack of commitment due to the temporary nature of their experience. Their presence impacted on the views of other external service providers relating to the professionalism of the service provided. This was a sensitive issue in the feedback discussion. The provision



of these placements had a financial incentive to the centre, but there was a shared appreciation that more active management of these volunteers was required.

There was a concern and subsequent commitment to focus on supporting family carers. The manager from her own personal experiences, but also the experiences of carers who had used the service highlighted this. The centre staff perceived these caring experience to be traumatic and previous interventions to provide support had felt to have provided only moderate success.

*'The staff feel that Meadow Day Centre is on the fringe of services which provide dementia care and that their input and potential input is marginalized.'*  
(Notes taken from reflection and action meeting, 170805)

The staff were very keen to link in with other services and to positively impact on dementia care for their clients and their carers. Participation in this research was positively valued.

## **5.8 Baseline Understanding of Almond Ward**

In order to summarise and highlight key findings a pen portrait of Almond Ward is included below.

Appendix 15 provides a summary of the baseline data collected from Almond Ward.

### **Almond Ward: a pen portrait**

The ward is part of a community hospital in West Lothian which is run as a Privately Funded Initiative (PFI) hospital. Almond Ward is a locked ward for thirty patients, predominantly for women with severe dementia but care is also provided for a small number of patients with other mental health problems (n=4). Clinical services are provided by the NHS but administration, support services such as catering and maintenance are managed by the PFI. The ward environment has many positive dementia care features such as safe outside

spaces, dementia appropriate signage, built around a circular track so there is no obvious entrance or exit to the ward. The physical space provides flexibility and choice for PWAD.

A feature observed by the researcher was noise levels. There were times when a number of clients were very noisy and that the general noise level could be described as distressing. On initial exposure to this, the researcher found this traumatic and seriously wondered about the impact of this on patients who are unable to move away from the noise.

At the point of conducting baseline data collection it was considered that nursing staffing levels were low. There was a core of staff that were stable and the ward manager had been in post for many years, nearing retirement. A Consultant Psychiatrist visited fortnightly and on weekdays a General Practitioner (GP) visited from the local practice. A positive arrangement was that only one GP Practice provided support to the hospital, they did not have to deal with numerous practices from across West Lothian. There was little input from Allied Health Professionals.

Patients are admitted from home via a Community Psychiatric Nurse (CPN) or consultant, from care homes, where there is a concern about their dementia care management and from hospital following assessment. Patients are either receiving continuing care, undergoing management of a dementia related problem and aiming to return to a care home or awaiting placement for a care home following assessment in acute hospital services. Both CPN and Social Workers are actively involved in those patients who are awaiting care home placement.

Assessment processes are in place appropriate to an NHS care of the elderly mental health unit. The assessments and care plans are well organised, numerous assessments are conducted routinely with each patient, for example nutritional assessments. There are no routine assessments for pain or distress.

A key nurse system is in operation for patients and the individual nature of this was stressed repeatedly during this information gathering process.

Person centred care approaches are evident in personal care for example food choices and activities. Monitoring behaviours is a key part of this for patients who have difficulty with verbal communication. Flexibility is offered in terms of getting out of bed and hygiene preferences. These decisions are discussed with family or through monitoring behavioural responses over time. Nursing staff debate the management of challenging behaviours and agree ways forward. It was agreed that this activity is not recorded appropriately, shared consistently, nor valued enough by nurses. Staff underplay their dementia care skills and knowledge and accept it as ordinary care. Staff feel frustrated that they are unable to offer more activities for patients.

The learning environment within the ward is positive. Staff are encouraged to take part in learning opportunities and via the ward manager care is discussed and debated. The ward manager has a discursive style and engages staff in debate about ways of caring.

The care provided by staff in Almond Ward is reviewed in a number of ways, through hospital audits and quality measures and from annual visits by the Mental Welfare Commission.

Staff engage with families in a number of ways, informal carers groups and ongoing follow up discussions between key worker and the main family member. Formal discussions are routinely held with family regarding decisions about flu vaccination and cardio pulmonary resuscitation. These discussions are held with the consultant, a senior nurse and family member, this was an example of good practice.

Almond Ward's REPDS facility profile had high scores across the seven domains. The reasons for this are that the service cares for women with severe dementia and a small number of patients have other psychiatric problems,

which require hospital care. The patients have a wide range of needs, from those who are independently mobile and need supervision with personal care to the care of the dying. Considering the client group, the scores for behaviour and psychiatric observations would have expected to have been higher (Details provided in appendix 15).

### **5.9 Feedback of baseline information at Almond Ward**

As described in section 6.7 above, information was fed back to staff at various times during the baseline data gathering. This took the form of sharing observations with them and asking clarifying questions. Once all information had been gathered a meeting was held with Bessie the Charge Nurse and Carly the Staff Nurse. Reflective notes taken from the feedback meeting, identified a sense of purpose, enthusiasm and an energy to participate in project activities.

There was concern expressed by Bessie and Carly about the levels of staffing in Almond ward, and that this may impact on the development work to be undertaken. They provided a number of examples where they felt they were compromising care as a result of low staffing levels.

The nursing staff were the driver for getting things done in the ward, they directed the activities of the visiting General practitioners and guided the Consultant Psychiatrist during fortnightly visits. They were well placed to influence change to their own practice. Within this community hospital setting they were the continuous force that co-coordinated all care interventions. The staff actively described and gave evidence for the fact they acted as the patient's advocates.

*'If we don't flag up our concerns who will speak up for these women....especially if there isn't family.'*

(Quote from staff nurse, reflection and action meeting, Meadow Day Centre, 180805)

The Charge nurse Bessie was a strong character who was deeply committed to providing a positive care situation and actively argued her case whenever possible.

Collecting the baseline understanding information highlighted that staff provided examples of positive person centred care practices. These were not necessarily identified as such, more regarded by staff as routine practice. A gap was present between what is known and done and what was consistent and documented.

Both Carly and Bessie had focused on pain assessment and management for people with a dementia for the next action phase of the research. They had discussed this with staff and argued that staff were keen to develop their practice in this area. Their aim was to achieve accuracy and develop in depth knowledge of pain assessment and management for people with a dementia. They also hoped for a shared, more formal way of working amongst the nursing staff.

#### **5.10 Reflection on the process of developing a baseline understanding of participating services**

Collecting the evidence to develop a baseline understanding of these two services was a lengthy and involved process. In retrospect a large proportion of this information could have been gathered whilst identifying need and planning an intervention, as opposed to a distinct and preliminary phase of gathering baseline data. The process outlined in this chapter took from April 2005 to November 2005, a period of eight months, however this related to completing this activity with the five services participating in the broader project. The author would argue that this information and the development of an overarching awareness of these services was beneficial and aided the consequent phases of the action research, however this could have been achieved with less specific detail and breadth of activity and importantly in less time.

The positive outcomes from this data collection process were:

- Development of working relationships with staff and volunteers from participating services.
- The researcher becoming connected to the services
- Gaining an understanding of how each service worked, particularly a previously unfamiliar social care service, namely Meadow Day Centre
- Staff gained exposure to previously unfamiliar assessment tools such as the REPDS, and the introduction of a dementia care evidence base.
- Feedback of baseline information provided the trigger for some immediate changes, namely changes to the environment such as the adoption of new signage and decoration, aimed at addressing the visual problems experienced by PWAD.
- There was time to carefully consider and debate the care issue to focus on as part of the next action phase of the research.

### **5.11 Conclusion: Analysis of findings from Almond Ward and Meadow Day Centre**

There were both commonalities and differences in regard to the analysis of themes following the conduct of developing a baseline understanding with these two services.

#### **Common themes**

Both services were keen to develop an evidence base related to their practice (supporting family carers and the assessment and management of pain for PWAD).

Evidence from the experiences of patients and family carers influenced their focus of practice development.

Both services had autonomy to take forward substantial practice development activity. The nursing staff led the service at Almond Ward and Meadow Day Centre Staff had provided evidence of instigating recent change independently, with minimal consultation.

Both services had positive environments that were beneficial to PWAD and their families.

Both services provided aspects of care, which were identified as consistently good practice however these were not regarded as such by staff. The good practices identified were regarded as ordinary and routine. For example deliberately and consistently offering choices and flexible approaches to care for PWAD and carers. In Almond Ward, the practice of staff consistently debating the potential causes of challenging behaviour then agreeing and testing out different approaches to care. This is consistent with demonstrable positive values and approach to contemporary dementia care.

#### Differences

Almond Ward was integrated within the National Health System, therefore practices were consistent with known best practice and local policy for in-patient units for older people with mental health problems. This was evidenced in their use of numerous assessment tools for nutrition and pressure sore risk. A system of regular audit and quality measures were in place to review their care practices. Meadow Day Centre, on the other hand, was evidently detached from other service providers, particularly health care providers, therefore they did not have the opportunities for joint learning and sharing of practice. They were independent in their management and consequently lacked connections with both social and health care services impacting on their exposure to evidence, research and ideas of sharing best practice.

#### **5.12 Understanding participants' beliefs and values about 1) Supporting carers of PWAD and 2) The assessment and management of pain for PWAD.**

This research activity followed on directly from the activities undertaken to develop a baseline understanding of the participating services, discussed above. At the end of the baseline understanding activities, the services

participating in the research had agreed and chosen a focus for the next phase of the research, namely the action phase. Meadow Day Centre chose to focus on supporting family carers of PWAD and Almond ward focused on the assessment and management of pain for PWAD.

As a precursor to taking action and developing an aspect of practice, there was a need to understand the beliefs and values of participants from both organisations, in relation to their chosen area of development but also to understand their ways of working as a team. The emphasis of this research is the attainment of practical knowledge and working towards outcomes that are useful in day to day practice. The aim is to develop an enhanced care experience for patients and their families (Meyer, 2000). The author would argue that conducting these focus groups about family support in Meadow Day Centre, and pain assessment and management in Almond Ward provided local and relevant information from staff, unique to their services. The nature of this information enabled practical and specific actions to be taken forward; moreover this information came from staff and volunteers themselves, therefore a further purpose of this participatory work with staff was to engender a sense of ownership and commitment to action.

### **5.13 Aims of beliefs and values clarification focus groups**

Beliefs and values focus groups aim to serve a dual function, they provide specific information for the researcher about how to proceed with an action, but in terms of participants in the research, the process enables engagement with a subject area and early stages of a change process. In an ideal situation participation of all staff and volunteers would be sought, however when this is not possible the aim would be to engage with as many as possible within limitations such as time constraints and the availability of staff. The purpose of this data collection is to clarify beliefs and values from the unique perspective of participants but in the process raise awareness and understanding regarding the project issues under investigation.



To facilitate a sense of responsibility and ownership of the project activity and ground the discussions in the practices of each setting, the researcher co-facilitated focus groups with key workers from each service. In addition to discussing carer support and the assessment and management of pain, a further purpose is to discuss how change takes place and how the team works together. This data aims to identify future positive ways of working and initiating change within each service.

The overall purpose of these preliminary discussions is to ensure changes to practice, to be undertaken in the action phase of the project, are based on the beliefs and values of participants, in practice this means understanding priorities and ways of working.

#### **5.14 Developing beliefs and values questions for focus groups**

The first questionnaire focused on supporting family carers and was used to collect data at Meadow Day Centre. The second questionnaire focused on pain assessment and management for people with a dementia and was used during data collection at Almond Ward.

Both of these questionnaires were adapted from questions used by Dewar (2005) as part of a training manual that focused on partnership working between patients and relatives in older peoples care settings. The questions focus on both personal and corporate beliefs and values as well as questions relating to change and team working. Key issues about carer support, from a paper by Askham (1998) titled Supporting caregivers of older people: an overview of problems and priorities, presented at the World Congress of Gerontology, Adelaide in Australia, were used as the focus for the questionnaire at Meadow Day Centre. Issues identified by carers such as respite care, being prepared for a caring role, in particular the provision of information were incorporated into the questionnaire.

The questionnaire used at Almond Ward focused on the assessment and management of pain for PWAD and drew on themes outlined in a paper by

Frampton (2003). The themes explored in the questions included communication difficulties / barriers and pain assessment for PWAD, the need for pain assessment to lead to pain management and potential behaviours PWAD may present with when in pain. The issue of differences and or similarities between distress and pain were also posed in this questionnaire.

The beliefs and values questions focused on supporting family carers of PWAD and pain assessment and management for PWAD are included in Appendices 16 & 17 respectively.

### **5.15 Process of conducting beliefs and values focus groups: participation and facilitation**

Focus groups were conducted with staff and volunteers from each participating service. The groups took place at Meadow Day Centre and Almond Ward and included staff and volunteers from each site. The key worker from that service and the researcher facilitated the groups, the key worker led the discussion and the researcher acted as a scribe. In the absence of a key worker, both roles were conducted by the researcher.

Organisation of each focus group was undertaken and agreed with key workers and staff. It was important that this data collection process was conducted in such a way that would not disrupt or compromise care activities.

Prior to commencement of the focus groups, participants were provided with information letters about the research and asked to sign a consent form. Participants had a copy of the questions and the discussion was recorded on a flip chart. The focus groups were not audio recorded as the number of focus groups conducted for all five of the services participating in the broader project, were too numerous (n= 24). The data required from the focus groups needed to capture key points identified and agreed by staff, rather than data that would require in depth analysis and theming. Appendix 18 identifies information regarding those who participated in beliefs and values focus groups at Meadow Day Centre and Almond Ward.

Following the focus group a report was made of the discussion and returned to each participant for checking. Participants were asked to check the report for accuracy but they were also invited to add any new information that had occurred to them since participating in the focus group.

On completion of the focus groups a meeting was held with the key workers from each service and all the focus group data was reviewed. The data was analysed collectively and key issues were debated and agreed. This involved identifying commonalities and summarizing repeated themes in the data. Following on from this, a planning process took place, to identify the interventions for the next phase of the project, namely the action phase.

#### **5.16 Key beliefs and values identified from focus groups at Meadow Day Centre**

##### **Supporting Carers of PWAD**

The statements, which staff from Meadow Day centre made regarding their beliefs and values about supporting family carers, are included in Appendix 19.

In order to highlight and summarise the particular beliefs and values statements expressed in regard to supporting carers of PWAD the following abstract has been compiled.

The overall approach to supporting carers at Meadow Day Centre focuses on the belief that each carer is individual and therefore support should focus on their specific needs and goals. It is important not to make assumptions about the support individual carers may want and to ensure individual choices are upheld.

In order for staff to support carers of PWAD, they need to foster positive relationships with the carer, this will require continuity, identifying members of staff with responsibility to undertake ongoing support work with carers. There is a need for staff to enhance their knowledge and practice in dementia care in order to provide a professional service.

Support offered to carers should be flexible and meet individual need. Options of in-house support should be available, such as the provision of a comprehensive range of information leaflets and a carer's forum where people can meet, support and learn from one another. Access to external support activities should also be signposted by staff. There is a need for the centre to have better links with other external services to enhance carer support by improved flow of information and increased awareness of support mechanisms.

#### **5.17 Implications from beliefs and values findings (Meadow Day Centre)**

These findings indicated that any development aimed at supporting carers of PWAD would have to acknowledge the uniqueness of each caring situation and that choice and flexibility were important. The manager of the day centre had encountered negative experiences where services had assumed a family member was a carer. This strongly influenced the perception of staff and volunteers.

There was an identification that the day care service should focus positively and engage with each individual client. Their day care experience should be stimulating, enjoyable and safe and as a direct result of this, carers would experience support. At a fundamental level, this support took the form of protected time for the carer.

Developing practice in the area of carer support would need to address the beliefs and values identified about identifying carer need then providing individual support, but also for staff and volunteers to develop enhanced knowledge and care practices regarding dementia care and carer support. It was evident that peer support from fellow carers was highly valued by staff at the day centre and an avenue they wished to pursue.

The staff perceived that external agencies, such as the local community psychiatric nurses, did not understand or value their service, in order to develop carer support at the day centre this could be viewed as a barrier and an area requiring intervention and development.

## **5.18 Key beliefs and values identified from focus groups at Almond Ward**

### **Assessment and management of pain for PWAD**

The key beliefs and values statements identified by Almond Ward are included in Appendix 20.

In order to highlight and summarise the particular beliefs and values expressed in regard to the assessment and management of pain for PWAD, the following abstract has been compiled.

The overall aim of care is to try and achieve the best possible quality of life for women cared for in Almond Ward. There is a need to take a holistic approach to pain care and involve family, nursing staff of all grades and doctors.

Due to the multiple problems experienced by patients such as memory loss, receptive and expressive communication problems and altered perceptions; staff have a responsibility to act as advocates. This means knowing the person well, particularly being aware when something has changed, such as the words / sounds used, postures adopted and usual behaviours. Nurses need to look for physical causes of pain, e.g. constipation, dental abscess, look for the available evidence. Distress and pain go hand in hand, it is difficult to know the difference, and this is complex work.

It is important to work as a team to find out what is happening and we need a formal, ongoing process to help us assess and manage pain and provide us with reassurance that we are doing what we can. We need to provide relief when a patient is experiencing pain or distress.

### **5.19 Implications from beliefs and values findings (Almond Ward)**

The development of care practices in regard to pain assessment and management would require particular consideration of team working and formal processes of pain assessment. Such developments would have to incorporate knowing and understanding individual patients, their behaviour and body language and the relationships between nurses and patients. Taking these issues into consideration would attempt to address the complex and very difficult communication challenges presented by patients on Almond Ward.

The notion of distress and its relationship with pain is complex and difficult to understand for individual patients with communication problems. There was a wide range of differing beliefs and values in regard to this and this lack of clarity could negatively impact on the management of patients. Namely patients receiving analgesia when they are presumed to be in pain when they are actually experiencing distress from another cause.

## **5. 20 Common themes arising from Beliefs and Values Focus groups**

A striking commonality between both services and their espoused beliefs and values relates to an absolute focus on developing knowledge of the person with dementia and the family carer as an individual but within the context of a relationship. This activity is key to enhancing assessment and management of pain and to the family carer's experience of support.

A further commonality was the value attributed by both groups of staff to their team working. In particular their organisation and processes, involvement of available team members, and enhancing their collective knowledge of the subjects under investigation.

Following completion of gathering baseline data activities an in-depth understanding of both participating services had been developed. Completion of beliefs and values focus groups identified what services providers thought about their existing service, what they wanted to develop and how they approached and managed change. These discussions were particularly focused on the subjects: the assessment and management of pain for PWAD (Almond Ward) and supporting family carers (Meadow Day Centre). With these stages of the research complete it was appropriate to move into the action phase of the work where each service considered available evidence, then actively took steps to enhance their focus of palliative care and make direct changes to practice. Chapters six and seven will present the findings and analysis of this work with both participating services.

### **6.1 Literature review: The assessment of pain and distress for people with a dementia (PWAD)**

#### **Introduction to section 6.1**

This section begins with an exploration of literature reviewing the numbers of people with a dementia who experience pain (6.1.2). Definitions of pain and their applicability to dementia care are examined in section 6.1.3 In section 6.1.4 research is debated that proposes PWAD may have an altered sense of pain. Section 6.1.5 focuses on the challenges of assessing pain for PWAD who have difficulty communicating. The literature review shifts in section 6.1.6 to reviewing a broader notion of distress and how this may be a useful starting point for assessment rather than focusing specifically on pain for PWAD. The benefit of a group of carers completing assessments is also introduced. The section concludes with a review of evaluation research of assessment tools used for PWAD.

#### **6.1.2 The extent of the problem: how many people with dementia experience pain?**

As described in detail in section 3.1, it is acknowledged that the number of people with dementia rises annually within Scotland (Scottish Executive Health Department, November, 2004). The population is ageing and the number of older people is rising. It is known that the majority of people who have a dementia are over sixty five years of age (Gow and Gilhooly, 2003), as a consequence of these population demographics, there will be an increasing numbers of PWAD. These statistics are not only relevant to Scotland but the United Kingdom as a whole. McClean (2000) highlighted that people with a dementia are likely to experience the same health problems as other older people. Tsai and Chang (2004) estimate that up to 84% of older people experience a form of chronic pain. Herr (2002) states that between 25 to 85% of community dwelling older adults experience pain. McClean (2000) identified cancer, arthritis, heart disease, stroke and osteoporosis as conditions that can



result in pain for older people. PWAD will experience these as well as the problems associated with their dementia. With the evidence of these statistics it can be argued that pain assessment and management is an important area in which further research is required, thereby increasing our understanding and enhancing the pain care that can be provided.

There is a body of literature which highlights undetected and untreated pain for PWAD and recognises pain assessment as a significant clinical challenge (Cunningham, 2006 Morrison and Sui, 2000 Weiner, 1999 Lefebvre-Chapiro, 2001 Krulewitch et al, 2000 Kovach et al, 2002 Scherder et al, 2005a). The prevalence of pain for PWAD in long term care settings is highlighted by a number of authors, Weiner (1999) highlights prevalence figures as high as 83%. Ferrell (1990) identified that 24 % of nursing home residents were in constant pain and only 29% reported no problems with pain. Other authors indicate that 40% to 80% of people in long term care facilities experience pain, (American Geriatric Society 1998, Cutson 2001, Thomas et al 2001). These challenging statistics highlight the need for research in this area, in particular how pain is assessed and managed within care settings.

The use of analgesics within nursing homes has been researched and findings indicate that people with cognitive impairment are prescribed and administered fewer analgesics than those residents with no cognitive impairment (Horgas and Tsai, 1998). Also within the acute hospital setting it was reported that PWAD received less analgesia following surgery for a hip fracture than elderly people with no cognitive impairment, PWAD received only a third of the opioid medication received by cognitively intact patients. Morrison and Sui's (2000) research in this area concluded that the majority of PWAD in their study were in severe pain post operatively. Many authors identified in this literature review argue the same points, this identifies a need to undertake further research in this area (Herr 2002, Scherder et al 2005a).

### **6.1.3 Pain a complex phenomena**

It is necessary to briefly identify a number of well known definitions of pain prior to reviewing literature and research pertaining to the assessment and management of pain particularly related to PWAD. Mobily and Herr (2001) describe pain as a complex, multidimensional, subjective, unpleasant and emotional experience that is mediated by sensory experiences and nociceptive events, and influenced by social, cultural and individual differences. This definition, although wordy, is comprehensive and highlights the multiple and complex issues at play when a person experiences pain.

McGuire (1992) identified six primary dimensions of pain, although these are old they remain relevant today, the dimensions were:

- Physiologic
- Sensory
- Affective
- Cognitive
- Behavioural
- Sociocultural.

These primary dimensions mirror the previous definition stated above, but in addition identify behaviour and affect as components of the pain experience.

Most famously McCaffery and Beebe (1989) provided a statement about pain that has been widely acknowledged, they stated pain as being, 'whatever the experiencing person says it is and exists whenever he or she says it does'. This statement places the focus of the assessment on the person and reiterates the individual nature of pain. The statement causes a dilemma for those with a responsibility of assessing pain with people who have difficulty communicating, the emphasis on self-report as the essence of a true assessment requires review and wider consideration. Smith (2005) comments that progress has been slow over the last 15 years in regard to developments of the measurement of pain for non-verbal people with severe dementia. In the absence of an individual verbal report, the focus has moved to observational methods as a way of identifying and measuring pain for this group of people.

#### **6.1.4 Do PWAD have an alteration to their sensory experience of pain?**

During my clinical experience of working with a variety of staff caring for PWAD, I have heard a view that PWAD experience less pain than those who do not have a dementia. This view is grounded on the memory problems PWAD experience, in that they can forget they are sore or when and how their pain started. There is also awareness that there are physiological changes in the brain due to a dementia related illness, that may result in an alteration of the perception of pain. Given both of these rationales it is understandable why these views are held. Both of these explanations have a degree of truth and reality however it could be argued that they grossly simplify what has been described above as a highly complex and relatively little understood phenomena.

A similar debate is also found within the literature surrounding the experience of pain for PWAD. Some researchers believe, and are investigating, the possibility that people who have the Alzheimers type of dementia, may experience an alteration in their pain experience and actually feel less pain than people with other forms of dementia, such as vascular dementia. The main author purporting this view is Eric Scherder (2005b). The rationale being, that a number of areas in the brain are affected by Alzheimers disease, the prefrontal cortex, the anterior cingulated cortex and the hippocampus. These areas of the brain are involved in processing the affective components of pain, therefore the potential for the experience of pain to be altered is a possibility (Scherder et al, 2005b).

This view is acknowledged but contested (Kovach, 2002 Morrison and Sui, 2000). There is a large body of literature that states PWAD experience pain, receive less analgesia than their cognitively intact counterparts and are considerably more complicated to assess due to an inability to self report and the impact of communication difficulties. Scherder's opinion is based on research, which utilised current assessment tools, it is argued later in this paper, that such tools are in need of development and further research,

therefore this raises questions as to the efficacy of these research conclusions. In terms of assessing risk, it is a dangerous assumption to make that PWAD of the Alzheimers type experience less pain. This belief could further limit the pain care already provided to PWAD. It could be argued that it is fundamentally wrong to make generic statements regarding a specific disease and its impact on the experience of pain. Pain as described above is widely recognised as an individual and subjective experience and is felt and expressed in many different ways by different people for a variety of reasons. Assuming a lesser degree of pain, for a group of people who find it difficult to communicate their pain experience, is a very high-risk approach that could negatively impact on the care received by PWAD.

#### **6.1.5 Assessing pain for people with a dementia**

Frampton, (2003: 248) argues that, 'a comprehensive, systematic approach to physical assessment in cognitively impaired older people is necessary not only to reveal covert pathology, but also to investigate and remediate symptoms such as pain.' The emphasis in this statement is the need for a comprehensive and systematic approach to assessment. Within the five services taking part in this research, none use a particular pain assessment tool and therefore an assessment, when completed, is the product of an individual member of staff. There are a number of common sense / pragmatic issues with this approach which are worth exploring. This individual approach limits the ability of the assessor to be comprehensive, as the views of other caring staff are not deliberately and systematically sought, and the absence of a tool affects what questions are addressed. The assessment relies on the individual's knowledge and skill of pain assessment and communicating with PWAD, in opposition to using a pain assessment tool based on predetermined criteria from a growing body of evidence. Within the participating services in this research, the majority of staff were unqualified or volunteers, therefore you could argue that a greater need exists for an agreed, structured approach to assessing pain, which will be a consistent guide to practice. A more structured approach increases the likelihood of accurate assessment, which as a consequence, enhances the opportunity for good pain management decisions. Without accurate

assessment information it is more difficult to manage pain, as there is a wide choice of treatment available. Giving a person inappropriate analgesia can have quite significant adverse reactions, such as drowsiness, constipation and hallucinations (Frampton, 2003). A robust, consistent approach to assessment is required and in light of research statistics about the numbers of PWAD experiencing pain, further research is needed to determine how this process is made real within practice settings.

Many authors identify the difficulties of assessing pain with PWAD as a result of their diminishing verbal skills due to disease progression (Frampton 2003, Ferrell et al 1995, Cohen-Mansfield 2002b, Smith 2005). As described above, pain has been defined as an essentially personal, private experience therefore the preferred mode of assessment is self-report. Understanding the person's description and experience of pain, but also what meaning is attached to this experience, is the optimal degree of information required. For those PWAD whose verbal skills are diminishing or have in fact diminished, this form of report is not available. Ferrell et al (1995) specifically considers the broader challenges of communication for PWAD, over and above diminishing verbal skills, these also impact on the person's ability to participate in pain assessment. Specific cognitive impairments in memory may hinder the ability to consider what the pain has been like during the course of a day, when it started, is it related to anything else and what the client thinks may be the cause of the pain? Other than stating the experience in the here and now, a memory deficit can impact on the information available. Inability to concentrate and maintain attention can also affect participation in an assessment. Loss of language (aphasia) and disturbances in visual spatial skills can further impede the ability to provide detailed information. These losses point towards the use of simple measures to assess pain, the use of abstract measures such as visual analogue scales, or assigning a number to describe the intensity of your pain, may be beyond the capability of some clients. Visual agnosias, where the PWAD no longer recognises everyday items for example cutlery or a toilet can also impact on the assessment process. Showing a PWAD a body map to locate the position of their pain may not be understood, the picture could be

misinterpreted or not recognised at all. It is evident from the arguments above that pain assessment is a highly complex process.

In considering all of these issues above it would seem that participation in pain assessment for PWAD is never possible, however this is not the case. The problems identified above affect people at different times during their dementia and to a lesser or greater degree. When taking the above challenges into consideration, the danger is to assume that no participation is possible. In the authors professional experience paid carers can take this stance and bypass simple questioning of the PWAD in preference to reporting behavioural observations that may indicate the presence of pain. This second hand observation is unnecessary when the client is able to answer questions. The essential issue in completing a pain assessment, which involves the PWAD, is an understanding of their individual, current communication abilities.

Cook et al (1999) broadens the discussion by identifying further elements which are barriers to the assessment of pain, they reports these to be: the reporting habits of older people, the acceptance of these reports by care staff and the inappropriateness of existing pain assessment measures. This indicates concerns regarding the validity of the self-report and responding with action to a complaint, which the assessor may feel, is inaccurate. A number of studies have identified that older people report less pain than their younger counterparts (Ferrell et al, 1990, Sengstaken et al, 1993). Closs (1996) identified from a survey of 208 nurses, that older people, when in hospital, are less likely to complain of pain. The author states that this is not because they are in less pain; rather they need to be given permission to complain of their pain. Brockopp et al (1996) surveyed 124 elderly people regarding their views about pain and pain assessment. Findings indicated that the elderly people felt that making a complaint of pain had implications, namely possible hospitalisation to investigate the cause of the pain. This would indicate a fear regarding the implications of complaining of pain. The people surveyed also thought that older people were not taken seriously when they complained of pain. Although this survey was small, the findings appear real and worthy of

consideration. A further scenario is that older people can minimize their pain, in the belief that pain is an inevitable result of older age (Lefebvre-Chapiro, 2001). Parmelee et al (1993) investigated people with cognitive impairment within institutional care and determined that this group reported less pain, particularly chronic pain than those without cognitive impairment. This result was striking as the group of patients with cognitive impairment studied had a greater degree of functional disability and physical illness than those without cognitive impairment. It is evident that there are a number of cultural and attitudinal barriers to the assessment of pain for PWAD.

Administering analgesia is not without complications, in situations when analgesia is given in high doses and a range of differing analgesics is used, severe complications can be incurred. These include nausea, constipation and opioid toxicity. Assuming staff are aware of these side effects, it can be understood why they would wish to feel confident of a report of pain before responding with analgesia.

Miller et al (2000) highlighted that nurses lack the knowledge and skills to assess pain in PWAD. In addition beliefs can be present such as PWAD are unable to report pain and more fundamentally, as described above, that they actually do not experience pain or the sensation is altered as a result of physiological changes caused by their particular dementia. Furthermore it is important to consider to what extent carers have received training in communication with PWAD. General communication skills in dementia are an essential component of undertaking pain assessment. Basic features of this communication, for example the use of closed questions and the avoidance of multiple questions, are an important component of an assessment. These issues are made more by the fact that a large proportion of those providing services for people with a dementia are volunteers or untrained members of staff. It is this group, which provide direct care and will have the most contact with clients, therefore be in the position of identifying pain. Within the five services participating in this research there are far more untrained staff and volunteers than trained members of staff. To serve as an example, within the

care home a normal shift has two trained nursing staff and five untrained carers. The trained nurses spend a large percentage of their time in drug administration and completion of documentation; hence direct care is predominantly the domain of the untrained carers. The issue of appropriate, supportive training for all groups of staff and volunteers is a necessity, particularly in regard to communication and pain care. This highlights a need to conduct research that focuses on practical and clinical processes which enhance pain assessment.

A further issue affecting pain assessment for PWAD is the manner in which staff discuss, review and act on their discussions, namely how decisions are made within a group of people who provide pain care. This is an issue of process, but one, which may be important in decision making. Much of the literature reviewing pain assessment focuses on the content and validity of an assessment tool, the person who conducts the assessment and the training required for the process to be effective. The author of this paper would argue, that few research papers look at the process of staff working collectively and systematically in this difficult area of decision-making in pain assessment and management. A number of papers highlight that nurses have a key responsibility in pain assessment due to their ongoing and direct contact with PWAD (Kovach et al 2000, Miller et al 2000, Weiner et al 1999, Cohen-Mansfield and Lipson 2002). As mentioned above, a large percentage of the nurses directly involved in this process may be untrained and this is acknowledged and reflected in the literature, which has researched interventions performed by this particular group (Snow et al 2004, Scherder and Manen 2005a). There are few papers which highlight and discuss the process of team working in this area. Particularly a process, that facilitates a team of carers to make pain care decisions for their clients.

It is helpful to ground this argument in reality, to serve as an example of the above scenario I will discuss the community hospital taking part in this research. It is possible that a lack of systematic discussion amongst the team may be hindering their decision making and reducing confidence in the



decisions that are made. The clients within this facility have moderate to severe dementia, a critical area of practice for the staff, is deciding the possible causes of distress experienced by their clients. This is a complicated and difficult process and, through discussion and observation held with staff, current practice tends to polarise staff into groups, those who feel a behaviour relates to pain and those who feel it is due to another cause. In the researcher's view there appears to be a lack of systematic information and forums where these discussions can take place. Within the community hospital very few other professionals are involved in the core team of nursing staff. GP's visit daily and a consultant psychiatrist visits approximately fortnightly. One nurse meets the GP and discusses what needs to be done. The charge nurse sees the consultant when he visits. Discussions seem fragmented and not inclusive of all the staff involved, potentially reducing the opportunity for more formal staff discussions. A further important issue is that a pain assessment tool is not used, making the information available, as described above, unstructured and individual to each nurse undertaking this activity. Research that addresses these practical issues is required to purposefully direct pain assessment practice. It would be necessary for the research methodology to have relevance to practice development. Later in this thesis the selection of an action research approach to address these practice related issues will be justified.

A further aspect of pain assessment is the active involvement of those that know the PWAD. In terms of continuing care settings, staff may have a long time to get to know the person, however initially the history that comes from the family, friends and other care staff, who have been involved, is very important. In assessment settings where PWAD are admitted for short periods of time, there is a real need to get to know the person as quickly as possible. Initial history taking is a vital part of this assessment. The level of history required from other parties will be dependant upon the information the person with a dementia can provide, they may be able to provide a wide range of valuable detail and this needs to be considered. The difficulties experienced by PWAD when they have been admitted to a care setting, can make assessment particularly difficult. Coping with a new and strange environment, meeting a

large number of new people and becoming part of an unfamiliar routine, can be significant stressors and cause distress, disorientation and increased confusion. Kovach et al (2003) described guidelines developed in 1998 by the American Geriatric Society Panel on chronic pain in older persons. The guidelines stated the need to include caregiver reports (caregiver could be a family / friend or professional carer) and that this was a compulsory element of any assessment. Previous carers can provide valuable information regarding analgesia taken and the presence of previous painful conditions. They may also be able to provide advice regarding interventions that have previously been used which ease pain, for example the use of heat pads and the use of movement, using different ways of positioning the body (Miller et al, 2000).

#### **6.1.6 The assessment of distress for PWAD**

It is important to change direction slightly and broaden this literature to consider the notion of distress experienced by PWAD. It is acknowledged that behavioural changes can be indicators of distress for PWAD, distress can be experienced as a result of many factors, misperceptions of situations, environmental factors, confusion, disorientation and emotional upset. A body of literature exists which identifies that PWAD experience behavioural changes as a result of pain or discomfort, Hall and Buckwalter (1987), Volicer and Hurley (1999). In addition when a PWAD is unable to communicate their pain as a result of the progression of their dementia, this can lead to behavioural expressions of distress, Volicer (2001) Kovach et al (1999). There is an important link here which requires exploration: can the assessment of a broader notion of distress assist with the assessment and management of pain and discomfort for PWAD unable to verbally communicate their experiences.

Watson et al (2003) have reviewed a process of assessing distress for people with a learning disability. This process has been set out to gather information in a systematic way which then enables a group of staff, or people known to the person, to go through a decision making process with the information available to them. A crucial issue is that the assessment process does not specifically focus on pain but behaviours associated with two phenomena: contentment

and distress, the aim of this process is to develop an understanding of what contentment and distress looks like for each individual. The tool is known as the Disability Distress Assessment Tool (DisDat), (Regnard et al, 2006). This is not to be confused with an assessment tool designed by Hurley et al (1992) to measure discomfort and known as the Discomfort Scale in Dementia of the Alzheimer's type (DS-DAT), a very similar name. The DisDAT assessment process appears to offer a most relevant approach for this clinical area, however it is detailed and initially may seem complex and unwieldy to use. It is interesting within a literature review for pain care for people with a dementia, that a tool designed for people with learning disabilities which is not primarily focused on pain, may be of particular relevance.

Key components of Regnard and his colleagues work are that, 'distress may be hidden but it is never silent', (Regnard et al, 2006: 2). In the context of learning disability, this statement infers that even when verbal communication is minimal, distress can be evident through signs and behaviours, which require understanding and interpretation by the person's carer. The similarities between learning disability and dementia in respect of this assessment process are evident. Furthermore, the authors have identified from previous research that no behaviours have been specifically attributed to pain therefore the research team felt it was essential to consider the broader notion of distress in the first instance before considering pain. The examples from practice recorded above highlighted this specific dilemma, whereby staff from the community hospital debated whether they were assessing pain or distress from another cause for the PWAD in their care.

In previous work, identified above, conducted by Hurley and her colleagues they also deliberately moved away from the term pain to the construct of discomfort for people with Alzheimer's disease. Discomfort was defined as, 'a negative emotional and or physical state subject to variation in magnitude in response to internal or environmental conditions', (Hurley et al, 1992: 369). The authors conceptualised this by stating, 'the presence of behaviours considered to express a negative and or physical state that are capable of being observed

by a trained rater unfamiliar with the usual behavioural patterns of the person', (p370). Observation of behaviour and a process of rating are the core activities here. It is difficult to comprehend that a person unfamiliar with the person being assessed would be able to make accurate judgements on their behaviour. This would be in conflict with knowing the person (Kitwood, 1997) and the complexity involved in observing and judging subtle changes in behaviour. When staff, who know a person well, as described in the community hospital above, find themselves debating what particular behaviours mean, it is difficult to consider how a stranger would succeed in this activity. It could be argued that a combination of skills is necessary, namely knowing the person and not only an ability to act as a rater. In recognition of Hurley's work, it served to consider a broader notion than pain, it focused on observation in the absence of verbal report and identified that behaviours can act as a window into the experiences of the person with limited verbal skills. It has served to act as a marker for other observational tools and it can be seen that the more recent DisDAT adopts some of these practices.

Research conducted by Regnard et al (2006) developing and validating the DisDAT, identified that a range of different distress cues were evident from their sample group of people with learning disability. There was no evidence that specific cues identified a particular cause of distress. What was interesting from this research was that different carers identified a different range of cues. The length of the relationship between the carer and person with a learning disability did not make a difference to the number of cues identified. It was however identified that a knowledge of the person was required to pick up early distress cues and thus useful in pre-empting an episode of severe distress. Regnard et al (2006) compared different groups of carers completing the DisDAT, including named nurse, key worker, another 3<sup>rd</sup> professional and a family member. Each of these carers identified a different number and type of cue for each person with a learning disability, however there was a core of distress / contentment cues recognised by all carers for each individual. This is an important finding as it highlights that each person with learning disability has a signature set of distress and contentment cues and a group of carers were

able to identify these. The implication of this finding is that a group of carers can contribute to an assessment of distress and contentment and collectively identify a core set of cues for each individual. There is potential relevance and robustness of assessment when a group of carers complete the assessment. This may provide alternatives to the gold standard self report of pain as identified by McCaffery and Beebe (1989) and may be pertinent for use with PWAD who have severe communication difficulties, particularly when the assessment of distress as a precursor to the assessment of pain may be relevant. There is a need for research related to the relevance of this approach specifically for PWAD.

#### **6.1.7 Pain and distress assessment tools for people with a dementia**

Within the last ten years there has been a variety of pain assessment tools developed, researched and presented in the literature. This indicates a need for practitioners and researchers to find a way through this difficult practice issue, but also confirms a significant clinical need. The dilemma and challenge which surrounds assessment tools focuses on reliability and validity, do they accurately measure and represent pain and its intensity for PWAD? What tools are relevant and can be understood by PWAD? A variety of research methods have been employed to address these questions. For example:

- Comparing the analgesia given to PWAD and cognitively intact elderly patients who have the same degree of painful conditions and are within care settings.
- Using a variety of assessment tools and recording the degree to which PWAD can appear to understand and use them (Hurley et al, 1992).
- Prospective, observational assessments, which compared self-reports of pain from PWAD and carers (Krulwich, 2000).
- Double blind clinical trials have been utilised, using placebo's and analgesia and a range of assessment tools (Kovach et al, 2000).
- Qualitative studies, which have examined the settings and behaviours of carers and PWAD and have attempted to understand the relationships,

interventions and decisions taken in relation to pain care (Kovach et al, 2000).

There is now a list of pain assessment tools available for clinicians, which have gone through various degrees of research. Within the geographical and practice context of this research, the tools most commonly referred to and discussed amongst participants were the Abbey Pain Scale (Abbey et al, 2002), the Doloplus II (Lefebvre-Chapiro, 2001) and the Disability Distress Assessment Tool (Watson et al, 2003 Regnard et al, 2006). A significant feature of each of these tools is the observation of behaviour as a means of identifying pain or distress. Herr et al (2004) has conducted a most useful critical review of 10 pain assessment tools. Their aims were, 'to identify and evaluate pain assessment tools for this population and to make available a description of these in terms of the following: conceptualisation, subject / setting, reliability and validity, administration and scoring, including a summary of strengths and weakness,' (Herr et al, 2004, p1). The work rated each assessment tool according to the above categories and the evidence available in the literature. The tools, which achieved the highest cumulative scores, were the DS-DAT (Hurley et al, 1992) and the NOPPAIN (Snow et al, 2004). The DS-DAT tool reviewed here is a different tool from the DisDat (Watson et al, 2003) mentioned earlier. A further analysis of each of the tools involved a comparison of the items in the tools with the criteria developed by the American Geriatric Society (1998) persistent pain assessment guidelines. The guidelines identify the elements which should be included in an observational assessment, these include:

- Facial expressions
- Verbalisations / vocalisations
- Body movements
- Change in interpersonal interactions
- Changes in activity patterns or routines
- Mental status changes

In terms of the preferred tools in this research, the review concluded with the following information: The Abbey tool was positively reviewed in terms of its ease of use, reportedly taking one minute to complete. It was criticised for the 'conceptual blurring', of acute or chronic pain and the authors suggest that further testing is required for reliability. A further criticism was the measuring of physiological parameters, for example temperature and pulse. Changes in these observations are not supported in the literature reviewed. A person with chronic pain (pain lasting more than 6 months duration) is unlikely to have altered vital signs as a result of the pain, this measure was not considered to be valid.

The Doloplus II was described as 'a comprehensive tool based on sound assumptions of the multidimensionality of pain' (Herr et al, 2004:1). It received criticism however, in that it was designed in France and there are potential translation issues, which have not been tested in English speaking countries. A further core criticism was that the assessment is based on the assumption that carers can reliably rate an older persons pain, Herr et al (2004) argues that this is not the consistent view of current literature.

The DisDAT tool was not included in the Herr et al (2004) review as it was not specifically designed for non-verbal older adults, and as identified earlier, its development was focused on people with learning disabilities and identifying the broad issues of distress and contentment and not specifically pain.

From Herr et al's (2004) work it would seem that the tools under review for this research have their limitations. It is fair to say that all the tools fell into this category, even those with the highest total scores. In general terms further research needs to be done with all of them. The implications for this research are that a selected tool needs to be appropriate and have high content validity in relation to the area of use. There is not a tool in current use, which meets all the defined criteria and is generally recognised as the best. As part of this research, it would be important to openly review the use of a selected pain

assessment tool, in order to further enhance both knowledge and practice in this area.

#### **6.1.8 Key messages from literature review: The assessment of pain and distress for people with a dementia (PWAD)**

- Pain is a significant problem for older people who have a dementia.
- The assessment of pain for PWAD who have communication difficulties is a complex and difficult clinical challenge. Slow progress has been made in this area of care over the last 15 years.
- For PWAD who have communication difficulties, the Gold Standard of self-report of pain may not be possible, alternative assessment in the form of observing behaviours has been developed.
- Adopting a broader notion of assessing distress and contentment for PWAD may provide an alternative starting point that can ultimately identify the presence of pain.
- Adopting a systematic approach where a group of carers complete assessments for PWAD may identify a core set of cues for distress and contentment. The dynamic of this group assessment process may underpin a robust and accurate assessment in the absence of self-reporting.
- Assessment tools are under ongoing review, none have been identified as the most effective, the clinical situation and the abilities of the PWAD are factors that impact on the choice of assessment.

#### **6.2.1 Assessment and management of distress and pain for PWAD: findings and analysis**

The findings and analysis in this chapter will be presented in two main sections:

6.2 The complexity of identifying distinct causes of distress and pain

6.3 Findings identified from implementing the Disability Distress Assessment Tool for PWAD.



### **Introduction to sections 6.2 and 6.3**

In section 6.2 data will be presented that highlights the complex process of assessing PWAD who are in the advanced stage of their disease and who have severe communication problems. In particular the challenges nurses and the researcher experienced, identifying a specific or dominant cause of distress from the observation of behaviour. This finding has a direct impact on assessment processes adopted by nurses, specifically their expectations of conducting accurate assessments, which leads to the effective management of patient problems.

In section 6.2 findings and analysis will be presented in regard to the implementation of the DisDAT on Almond ward for PWAD. The DisDAT is an assessment process developed for people with a learning disability to identify behaviours when distressed and when content. The overall aim of the DisDAT is to enable carers to problem solve when behaviours that represent distress have been identified. There has been minimal research to date of using the DisDAT for PWAD. The DisDAT is included in Appendix 21.

### **Data collection and research context**

The findings and analysis presented in this chapter arose from data collected at a community hospital, more specifically from one ward in the community hospital that provides care for women with advanced dementia. For the purposes of this thesis it will be referred to as Almond Ward. In respect of baseline data gathered from this service the results and analysis are described in chapter five. The beliefs and values expressed by staff, regarding the assessment and management of distress and pain experienced by PWAD are also found in this chapter.

Almond Ward was directly involved in the action phase of the research from May 2005 to June 2007, a period of 25 months. Multiple data collection

methods were used during this phase, these are described in detail in chapter four; research methodology and methods.

Within this chapter different voices are heard and presented as evidence. This is in keeping with first and second person enquiry (Reason and Bradbury, 2008). For example the researchers voice, (first person enquiry) is presented as evidence in the form of;

- Reflective accounts
- Reflection on baseline data
- Notes from participant observation

Second person enquiry is identified from the following evidence gathered collectively with participating staff and families;

- Reflection and action meetings
- Interviews with daughters of patients (Morag and Avril)
- Final evaluation meeting
- Case review meeting
- DisDAT training session

## **6.2 The complexity of identifying distinct causes of distress and pain**

The data gathered which lead to the findings presented in this section included two case studies, this involved family interviews, participant observation with patients, regular reflection and action meetings with key staff from this ward and the researcher's reflective accounts.

*We then unexpectedly moved on to talk about a particular case of a lady in the ward who has problems with pain. Carly showed me the case study she had worked on for the action learning meeting that she had been unable to attend due to staffing! She had done a lot of good work on this. It described a lady who complains of pain in her knees and general joint pains. Her mobility had deteriorated recently and she has a bursitis on her elbow. She is anxious and persistently seeks out staff for all sorts of reasons but talks to staff a lot about pain. The staff struggle with the cause of this lady's distress, is it pain / anxiety / attention seeking behaviour? Bessie and Carly had a real debate about this lady and the cause of her problems.*

(Notes from reflective account, p2, 101105)

The above data was taken from a reflective account following a reflection and action meeting with the Charge Nurse of Almond Ward, Bessie and a staff nurse Carly. These nurses formed the core research team on this ward. The above data highlighted a key issue in this research; namely the small but consistent number of patients on this ward who, in the opinion of the nurses, were experiencing some form of distress but the cause of the distress was uncertain, this situation fuelled anxieties and debate amongst nursing staff. Regular reflection and action meetings with these staff identified the continuous nature of this problem.

The patient described in the data above, actually represented an atypical situation in that she did not have difficulty with verbal communication, she was able to articulate her problems but it was her complaints that caused concern. A more usual scenario, incorporated the following factors, a patient with advanced dementia, who has severe difficulties with communication and who exhibited a behaviour that concerned nursing staff. During the period of research on this ward there were consistently one or two patients in this situation. Identifying the distinct cause of their problems and managing them, was a source of concern for nursing staff.

In accordance with a democratic and participatory approach to action research with Almond Ward, a key decision was made with the core group and other ward staff to focus on the issue of distress rather than pain. This was not the original plan however was decided in response to a practice need. A fear existed within participants that focusing directly on pain may pose a risk of missing broader problems that cause distress. This would not mean that the issues of assessing and managing pain for PWAD would be ignored rather it would take more of a back stage position, with distress taking the front stage in this action phase of the research.

*Positive and commendable person centred dementia care activities are not valued as such by staff. Good examples were provided, staff working on the ward may not see the bigger picture and understand that this is good practice and is important to acknowledge but also formalise and develop. This type of care is what Almond Ward is all about, therefore its acknowledgement and formalising into care plans*

*and written documents is important.....In general the way care is written about doesn't seem to reflect what is known about the patient and how care is actually given. I have a sense that patient documentation is superficial and routine covering the basics.....this may hamper overall communication and consequently the effectiveness of care.*

(Notes taken from reflection of baseline data gathering, p5, 180805)

*We discussed each of the four tools. Firstly the DisDAT, both Carly and Bessie felt this tool provided baseline information, although it is not specific to pain but is specific to identifying clients when they are and are not distressed. It would be very appropriate for use on Almond Ward. Stephen pointed out that it would have challenges, it required discussion amongst staff, in a formal discussion way, how would this take place? When and with whom? Therefore it was not only a paper exercise but a way of making decisions following a structured assessment process.....the DisDAT tool was considered to be the most appropriate. It was agreed that the tool would be relevant to use on every patient on Almond Ward and that we need to agree guidelines for using the DisDAT on the ward.*

(Notes from reflection and action meeting, p1 & p2, 310506)

The above data highlights a key reflection of the researcher and a conversation that took place at a reflection and action meeting with Carly and Bessie. In combination these changed the focus of the action phase of the research in response to the clinical and practice needs of the service, focusing primarily on distress.

The following data returns to the complexity of identifying distress for PWAD in Almond Ward. The abstract below was taken from data collected whilst undertaking participant observation with Morag.

*She had breakfast but during this her demeanour began to change. She seemed to me to respond to the shouts of other women round about her and there was one woman particularly, in the next bay, who was shouting out and swearing and Morag (patient being observed) was clearly responding to her. She was hearing her and looking up as if to see where the noise was coming from. She started to look more agitated at this point and it is difficult to know whether it was the sounds round about that triggered this but I think they were certainly involved in some way.*

(Notes from participant observation, p1, 141106)

This abstract highlights the researcher's observations and analysis of the situation. There is an association drawn between the environmental factor of noise and an increase in Morag's agitation. During this observation this patient's agitation escalated to a very severe level where she was shouting, swearing, and hitting out at staff. She threw a tray across the room and in an attempt to hit one of the nurses she fell to the floor. It took around 30 minutes

for her to slowly calm down. During this episode the staff employed de-escalation techniques and the researcher's interpretation of what was observed was that nurses adopted a calm and professional manner in the management of this situation. As a researcher it was an upsetting experience to see a frail, elderly woman experience this level of distress. The impact on other patients around her was clear, those who were able got out of the way and left the situation, and some, but not all of those who were left, displayed distressed behaviours. Although as a researcher, the observation identified strong links between the patient's distress and noise it was very difficult to identify any other background problems, which may have contributed to this degree of distress. For example, could she have been experiencing underlying pain? During this observation there were other behaviours displayed by this patient, which pointed towards other potentially distressing stimuli.

*One of the other nurses MR came round to the sitting area with the drug trolley and she (Morag, patient being observed) seemed to be quite directed towards her, she shook her fist at her and looked quite angry and agitated. She also did this with me as I was sitting opposite her helping another patient to have her breakfast. She would look at me and sort of shake her fist and there were a number of occasions where she was definitely swearing and she would say, 'oh bugger' and 'oh Christ'. (Notes from participant observation, p1, 141106)*

From this observation Morag appeared to show other potential triggers or responses related to her experience of distress. To highlight this, the following potential reasons for her distress are stated below. Potentially these included issues of perception of what was around her. Her anger was focused on a staff member in uniform and a drug trolley. It is perceivable that they represented images related to past negative experiences and could have provided a focus for her agitation. As a researcher I had worked with her on a number of occasions but could still have been unfamiliar to her and my appearance was very different to the other elderly women in the room. My presence was also a focus of anger. Her anger was not directed at any of the patients in her vicinity although when she stood up and walked round the room she held on to their tables and chairs, knocked over cups of tea and plates of food. She appeared oblivious to the presence of patients around her apart from when they protested against her actions. Her swearing was noticeable in that she ordinarily spoke

very few words and this seemed to clearly represent a sense of frustration. She could easily have been experiencing discomfort or pain as she was a very frail lady for whom movement was difficult and she may have experienced stiffness and pain. There are also a number of other potential physical reasons that could result in this experience of distress, such as constipation, dehydration, and infection. The purpose of stating these potential causes of distress, in regard to this period of observation, is to highlight the complexity of the situation and the difficulty of specifically identifying what was causing her distress.

It is evident from the data of participant observation and reflective notes stated above, that identifying distressed behaviour, then identifying potential causes is complex. As a consequence of these factors it is perhaps predictable that this situation raises debate and differing interpretations from nursing staff. Factors such as consistency of staffing, consistency of observation and the documentation of these incidents as well as the skills and experience of nurses are all key factors at play. In the observation stated above one nurse observed this escalation of agitated behaviour whilst administering medication to patients. It is evident that over time, a variety of nurses will observe different things and potentially interpret them in different ways.

A theme observed regarding data collected from baseline data, reflection and action meetings, participant observation and the researcher's reflections was that the Charge nurses' views appeared to hold more weight, whether or not her arguments about the cause of distress were stronger than other members of staff. She was the most vocal member of staff and dominated discussions about symptoms and nursing management. This coupled with a genuine respect from nurses on the ward, of her experience and skill resulted in a situation where she had dominance in terms of decision-making. An element of hierarchy and power was therefore a further factor in the debate and decision-making processes of nurses about the cause of distress.

During an interview with Lynn, the daughter of Morag, a family member's interpretation of distress was raised.

*Lynn talked about an episode a couple of weeks ago when she thought her mother might actually be in pain. She (Morag) did not try to communicate at all and her voice sounded tired. Lynn asked her mum if she was in pain. She did respond saying 'no', however Lynn was aware that she says no to a lot of things and that this is not necessarily accurate. Lynn had difficulty describing what she looked like, other than she just didn't look right, that there was something different about her. Lynn spoke to one of the nurses and asked if she thought her mum was sore, also if she was OK and how she had been that day. The nurse felt things had been OK that day but she would discuss it with the night staff and they would keep a close eye on her.*

(Interview with daughter of Morag, p5, 220207).

Lynn's observation of her mother's behaviour made her consider the possibility of pain. Lynn had been a carer for her mother prior to admission to hospital and visited her regularly whilst she was in Almond ward. She knew her mother very well and was accustomed to interpreting the meaning of her behaviour. The phrase, 'she just didn't look right', was a phrase commonly used on this ward during the research. Both families and nurses used this to articulate a change, which concerned them. It represented an intuitive response to an observed change in a patient's behaviour. The above data highlights, that even for someone who knows a person intimately over a long period of time, identifying meaning behind a behaviour can be extremely difficult to articulate and distils to a hunch or a sense of something. In this case Lynn felt her mother was different, she didn't try to communicate and her voice sounded tired. In terms of these specific observations it is difficult to rationalise why Lynn thought her mother was in pain. On this occasion the nurse in question had not identified any similar concern. If a patient's daughter, who knows her well and regularly spends individual time with her, is working on a hunch that something is wrong and struggling to be clear about what she is seeing, how much more difficult it will be for a team of nurses, who work different shifts and have different abilities and perceptions to agree that a patient is experiencing pain or distress?

During a second case study on this ward, Avril the daughter of another patient called Nancy, identified a similar situation.

*Avril (daughter) felt that she would not be able to recognise distress so much now as she (Nancy, her mother) is not so aware of what is going on around her as before – it's hard to tell now, as there is a lot less reaction to what is going on around her and much less response than there used to be.*  
(Interview with daughter of Nancy, p1, 091006).

As time had progressed and Nancy's dementia had advanced, Avril found it more difficult to determine whether her mother was experiencing distress. Avril had been her mother's carer and was a very frequent visitor to the ward therefore she should have been in an effective position to comment and make deductions from observations of her mother's behaviour. In reality however this was not the case and Avril felt less confident as time progressed.

The following data was taken from the researcher's participant observations with Nancy.

*During her evening meal .....I felt she was the most agitated I have seen her. Her agitated behaviours were more continuous and that she was awake .....she was moving in her chair, putting her hand out as if to touch something.....or leaning forward and making repeated noises.....she had a frown on her face and a sort of lost look in her eyes and she was clearly listening to what was going on around her. She would look at people as they passed her or responded to other patients as they shouted out loudly. This was the busiest it had been all day.....a number of patients were really shouting out quite noisily..... there were also a number of visitors around and nursing staff. .... so generally a very busy, noisy and active environment. It is possible that this may have caused her some distress but again very difficult to know.*  
(Notes from participant observation, p4, 091006)

The above extract highlights the researcher's observations of Nancy's distress. It is evident that potential environmental factors were considered as potentially triggering distressed behaviour, however the researcher's ongoing uncertainty of these triggers is evident.

*Shona (staff nurse) felt that the case studies had picked up more in terms of behaviour and distress / pain than the staff, or Shona, would have picked up in ordinary day to day care. There was a higher level of detail however we discussed that when you are working and dealing with a multiple group of patients and performing various tasks, it is difficult to have this level of observation and in some ways the case studies and Stephen's (researcher) observations were, to a degree unreal, in that Stephen spent many hours with each of these ladies.*  
(Notes from reflection and action meeting, p2, 090107)



This data emphasises the practical challenges nursing staff experience observing behaviours of patients in this setting and identifying what triggers particular distressed behaviours. Although the researcher had spent many hours observing these two women, he had only been working with them for a short period of time however the in depth nature, focus and quality of the observation was noticeably different to the level of observation the nurses were able to undertake. This surprised the researcher as he had assumed that the relationship between nurses and patients over time would have made these types of observation commonplace. In reality the busyness of the area and multiple activities to be completed by nurses had an impact on the level of observation possible. Potentially auxiliary nurses would have spent more direct time with patients as trained nurses are required to undertake many activities which involve time away from patients, for example completing patient records.

#### Summary of key findings in section 6.2

In conclusion the findings and analysis from the data presented in this section has highlighted the following:

- How complex it was to interpret and understand the distressed behaviour of a person with advanced dementia who also has severe communication difficulties.
- Focused and in-depth observation of distressed behaviours by an experienced and knowledgeable nurse (researcher), provided potential but not specific causes of distress, leaving a sense of uncertainty in regard to the cause of the distress.
- Family members who knew the PWAD well could not identify specific causes of distress or pain. Lynn interpreted her mother's appearance and behaviour (she didn't look right, tired voice and no communication) as meaning she may be in pain. This evidence appeared vague and nursing staff had not identified a potential problem of pain or a change in her behaviour.
- Avril, who had previously been her mother's carer and who visited frequently, struggled to identify specific causes of distress and pain

because she felt her mother had changed so much, there was much less reaction now, she no longer knew whether her mother was distressed.

- The evidence presented above points to a very challenging situation for a team of nurses on this ward as they attempt to observe for signs of distress, understand the cause of the problem and take effective action.

Section 6.2 which follows will describe and analyse what action was taken by nurses to address these issues.

### **6.3 The implementation of the Disability Distress Assessment Tool (DisDAT) for PWAD.**

#### **Introduction to section 6.3**

This section will present findings and analysis in regard to the implementation of the DisDAT on Almond ward. The DisDAT (Regnard et al, 2006) is an assessment process developed for people with a learning disability to determine the individual behaviours of a person when distressed and when content. The overall aim of the DisDAT is to enable carers to problem solve when behaviours that represent distress have been identified. This research sought to evaluate the implementation of the DisDAT within a different context, namely PWAD rather than people with a learning disability.

The following key findings will be presented in this section:

- The DisDAT, within this dementia care context, provided a person centred approach to assessment and was in keeping with the practical application of theories regarding person centred dementia care.
- The term distress, a fundamental component of this assessment process, was found to have different interpretations and meanings for nurses on Almond Ward. Debating and agreeing what distress meant within the context of Almond ward and the patient group was a crucial process in implementing the tool.

- Nurses found working with a broad notion of distress to be advantageous, rather than for example, deductively focusing on a specific problem of pain, potentially missing another separate problem experienced by patients.
- Completing the DisDAT required the participation of a group of nurses who consistently worked together. In this context the face validity of the tool was felt to be high and nurses expressed confidence in this process.
- The DisDAT was a useful and appropriate assessment tool for a continuing care setting where nurses had time to get to know patients well. Relationships with patients and relationships amongst staff were a crucial aspect of using the assessment tool.
- Implementing the DisDAT raised expectations amongst staff that the management of distress and pain would be easier. In reality a completed DisDAT provided robust and comprehensive evidence for treatment decisions. Clinical judgement however was still required and decisions remained difficult, reflecting the complexity of care for PWAD who have severe communication difficulties.

### **6.3.1 Implementation of the DisDAT on Almond Ward**

The DisDAT tool was selected for use by staff on Almond Ward. A range of pain assessment tools, appropriate for use with PWAD, was provided for staff to review. The DisDAT was included in the assessment tools available for staff to review. Despite the DisDAT not identified as a tool specifically for assessing pain, it was agreed with staff that they could consider this as an option in light of data generated from the baseline understanding phase of the study. Data highlighted a need for an assessment tool that helped staff to identify causes of distress for PWAD and potential ways of managing this distress.

Following selection of the DisDAT, the key staff working on the project, agreed an implementation process. Articles about the DisDAT were made available to

staff to read and discuss. Implementation involved training in the use of the tool. Groups of staff met together and completed the tool in respect of a patient they knew well, usually a patient within their key worker group. This was a challenging task but important learning occurred during this process, namely that it was difficult to complete the DisDAT in this way. It required to be conducted whilst you cared for the patient. The detail required was specific and behaviours needed to be witnessed, in the moment, in order to complete the assessment accurately. These issues are discussed in more depth in the following sections in this chapter. All nursing staff participated in this training, including health care support workers and registered nurses.

In conjunction with this training, guidelines for use of the DisDAT in Almond Ward, were developed by key staff. These reflected the challenges experienced by staff completing the DisDAT during the training sessions. The guidelines were revised after an initial draft was reviewed by staff. The guidelines were made available to all staff and key workers discussed these with members of their team. Guidelines for use of the DisDAT in Almond Ward are included in Appendix 20

Following completion of the training sessions and dissemination of the guidelines, a process of completing the DisDAT for patients was undertaken. Initially key staff involved in the research from Almond Ward completed the DisDAT for their patients. The rationale for this was they had the most experience of the tool (conducting training and compiling guidelines) and should be the first to use it in practice. Limiting key staff to completing the tool in the first instance, also meant that challenges could be considered and adaptations to the assessment process made prior to rolling this out to other staff members. It also provided an opportunity for key staff to role model and determine their commitment to this assessment process.

The sections that follow highlight the findings identified from this implementation process. The implementation process took time, specifically in

regard to the complexity of the tool itself and attempting to engage as many staff from the ward as possible.

### **6.3.2 The DisDAT, a person centred assessment tool**

During reflection and action meetings, nursing staff from Almond Ward specifically described the tool as person centred. Their descriptions of the actions taken to implement the tool and their early experiences of using it point towards a tool that is focused on the person and therefore provides information of an individual nature.

*What has changed within your service? We now have an assessment tool in place, which we can use to help validate our, 'I think she is in pain statements', and also use as a tool to monitor distress – more geared towards distress assessment..... It is now more person centred and the staff are more confident in dealing with these issues.'*

(Reflection and action meeting, p2, 230707)

*In terms of documentation (nursing) there is more specific information recorded and care is more person centred.*

(Reflection and action meeting, p2, 230707)

*Carly spoke of the DisDAT in terms of appreciating its structure and the focus it provides in assessing people and she likes thinking about the patients and their mannerisms in regard to the structure that is provided. She feels that staff are observing things in a different way, a more precise way than they did before.....There is a challenge in making all the signs individual for people and thinking about it more than they had done in the past.*

(Reflection and action meeting, p1, 010207)

It is evident from the last abstract of data that there are challenges in using a tool that is person centred. It is a complex process focusing on individual behaviours and interpreting their meaning. A good example of this was provided by data collected during a DisDAT training session with senior staff on Almond ward. During the training session the group completed the DisDAT for a patient who was well known to the staff and had been a patient on Almond ward for more than four years. This group of nurses had a knowledge of the principles of the DisDAT and had been actively involved in the selection of the tool, therefore they were committed to using it, although were novice in terms of experience of using it. The group specifically considered the vocal sounds made by this woman when she was distressed. The group were aware that she

made a particular sound which they all felt was linked to distress, but they were unable to articulate what this sound was like and furthermore translating the sound into a word or representing it with letters was not possible on this occasion.

*It was evident that this tool needs to be completed over time, in that whilst all the staff present knew the patient we were discussing, in some instances we struggled to find ways to express her behaviour. This is something you would need to be conscious of and go back and forward to complete whilst you are working with her and observing her behaviours. We felt that this was important learning and that this patient was well known to all the staff, but still we had debate about how we could describe particular behaviours.*

(Reflection and action meeting, p2, 190606)

Data collected from reflection and action meetings, DisDAT training sessions with individual staff and evaluation discussions, reinforced the idea that the orientation and design of the DisDAT directs staff to focus on patients as individuals, particularly their individual behaviour and the meanings associated with these behaviours.

*What has changed within your service (if anything)? We now have an assessment tool in place, which we can use to validate our 'I think she's in pain,' statements and also use as a tool to monitor distress – more geared towards distress assessment. We are more observant about issues of pain and recording this. It is now more person centred and the staff are more confident in dealing with these issues.*

(Final evaluation discussion, p4, 230707)

This assessment tool does not restrict or confine staff to assessing patients according to predetermined standards or measures, such as likert scales. The assessment criterion directs staff to inductively describe very specific behaviours such as the appearance of a person's eyes and jaw when distressed or content. It could be argued that this does represent a person centred approach to assessment and the consequent provision of care, however the complexity and utilisation of this approach, as described above, requires consideration in terms of application within a team of nurses working together and the context of the situation. In particular the ability of nurses to get to know patients in their care.

There are criticisms that person centred care, although a significant advance from the dehumanising medical model of dementia care, as criticised by Kitwood in 1997, does have its limitations. It has been argued that person centred care fails to acknowledge the important issue of relationships, interdependencies and reciprocities that underpin caring relationships (Nolan et al, 2003). The key argument against person centred care in this context is the 'skewed focus' on the person in isolation, omitting to fully recognise the reciprocal impact of who surrounds the person with a dementia, particularly in respect of the relationships of those who provide care. In terms of arguments promoting person centred care and relationship centred care, Nolan (2004) argues that respect for personhood is essential however this needs to be balanced and not privilege individual need alone. 'Relationship centred care in conjunction with the SENSES Framework makes explicit the importance of acknowledging and seeking to address everyone's needs in a way that person centred care does not' (Nolan et al, p131, 2006). Issues related to the strengths and challenges of person centred care and relationship centred care are explored in depth within section 2.1.

From the data collected from nurses working in Almond Ward, evidence pointed to relationship centred care being an important feature in the implementation of the DisDAT. During a case review meeting of a patient on Almond ward, examples were provided of relationship centred care and its impact on completing the DisDAT and managing distress. The case review was initiated with the purpose of having an in depth discussion with a group of nursing staff. The focus of the discussion related to a particular patient nurses felt was experiencing distress and or pain.

*Carly had completed a DisDAT for Jessica prior to our meeting and this had helped to identify different behaviours, which triggered the thought that she was in some distress or pain..... We discussed this in some depth in that Jessica can tell you if she is sore. For example if you bump into her she would say, oh that is sore you have hurt my arm and so she had the ability to do that but she will also complain of pain when the staff are not sure that she is in pain. She does not have any particular family or visitors who would know her better than the staff, who would be able to help us with these decisions..... There was a degree of confidence in her changed behaviour (a shared view of the six participants in this discussion) in*

*that this does acknowledge some distress or pain and therefore it would be worthwhile to have an action plan in place.*

(Notes taken from case review meeting, p1, 200207)

The above data highlights that staff knew Jessica within the context of the caring relationships they had with her. Their knowledge was broader than knowing her as a person, they knew how she reacted and related to them interpersonally over time. Their concern regarding the occasions when she complained of pain but nurses were unsure of the reality of this complaint, provides an example of knowing the person within a relationship and having a sense that something is wrong.

The data also highlights that there were no available close relationships other than those she had with the staff. Family or friends did not routinely visit Jessica, therefore the relationships staff had with her, provided the available information they had to work on. This discussion highlighted that relationships were acknowledged to be valuable in understanding and working with Jessica and the staff had considered the question of who was available that knew her and what information could be contributed to the discussion.

### **6.3.3 The necessity of understanding the term distress for individual PWAD**

A working understanding of the terms distress and contentment for individual PWAD are critical in regard to completing the DisDAT. During a reflection and action meeting held with key staff, it became evident that following the completion of the DisDAT, a new understanding of the term distress had developed.

*We spoke about a lady on the ward and Carly felt she had to consider what distress meant for her, having completed her DisDAT, she had a different view from before, when she thought distress was of a very severe nature and you may not actually see distress in some of the women on the ward. For this particular patient though, distress was of a much milder nature but could still be recorded and identified as distress.*

(Notes from reflection and action meeting, p4, 090107).



The key member of staff Carly had a working assumption that the term distress referred to a top-level form of distress, namely behaviour of a very severe nature experienced by a few patients. This perception would significantly impact how she completed the DisDAT, as behaviours displayed of a lesser degree of intensity, according to Carly's own definition, would not be considered to be distress. She also identified a broad or generic view of distress, similar to a standard, which as well as being severe, was of a general level which any patient on the ward would have to reach in order to be classified as distressed. This view was not in parallel with the individual approach of the DisDAT, where distress is any behaviour, which in the opinion of carers does not represent contentment for an individual person. This was a very valuable and unexpected learning experience during the implementation process. In response to this new understanding, key staff were able to highlight perceptual issues of distress to other staff in the ward and clarify the individual nature of distress, which is the fundamental core of this assessment process.

My own reflections on this issue, identified from episodes of participant observation, were that the context and norms of patient behaviour, experienced within this ward, could shape the staff's view and understanding of the notion of distress. The following excerpt from a reflection and action meeting highlighted this issue.

*We also discussed the issue of when a patient is pushing you, it is better to be against a wall and as the patient pushes, less harm can be done because they cannot push you anywhere and you cannot be knocked against anything. Stephen highlighted that for many people to consider that happening to them in their work situation would be entirely unacceptable, but the nursing staff here are acclimatised to it, it is all within their perception of what to expect at work. This could have an impact on what they see as distress or contentment as they are used to seeing quite severe behaviours. In some ways the context and the values and beliefs of nurses are important within the activity of assessing contentment and distress and what the norms of behaviour and anticipated behaviours are present within different settings.*

(Notes from reflection and action meeting, p4, 090107).

The implications from this data would indicate that when introducing this tool to a care setting, there is a need to discuss and clarify what is meant by the individual nature of distress and contentment. It would also be pertinent to take

into consideration the context of the setting, particularly the norms of client behaviour as this could potentially impact on the working expectations and values staff have, in regard to the meaning of distress and therefore how to assess it.

*As the day progressed, I felt able to expect what she was going to be like and so expect what she was going to be like when feeding her and when we were moving or doing things with her and she was clearly at her most distressed while nursing interventions were going on and I would say she was at her least distressed while left alone in a quieter area when she was sitting in her chair in the morning. She did seem to clearly respond and look distressed after specific events, such as when cream was applied to her bottom, when she was being washed there was a very direct response. When she had one of the drop attacks, she very directly looked distressed and wondered what on earth had happened. I was able to determine a spectrum of contentment to distress but only within the context of this day that I had spent with her. You would certainly need to spend much more time with her to know if her level of distress was, or could be much more than this.*  
(Notes from participant observation, p4, 101006)

The above data was recorded during the first day of participant observation with Morag, a patient on Almond Ward. It is evident from these initial observations by the researcher, that elements of distress and contentment were clearly identified. More than this a spectrum was identified which included different levels of both distress and contentment. The purpose of highlighting this data is that when distress is viewed as an individual phenomenon, as was the approach used by the researcher, it was quickly and easily identified. For staff who are normalised to the setting and who over time develop shared values, the term distress took on a more collective definition and was therefore utilised very differently.

The researcher from an outsider perspective could identify potential distress with individual patients quite readily. In order for these observations to be validated, discussion and review with staff would be required. Carly, on the other hand, in the extract of data above (Notes from reflection and action meeting, p4, 090107) had a view that she may not see evidence of distress at all in some of the patients, a very different perspective.

Different care settings may hold a variety of beliefs and values about the term distress that may or may not be explicit, therefore an initial clarification process would be important prior to implementing the DisDAT.

### **6.3.5 Working with a broad notion of distress rather than focusing on a specific problem such as pain was advantageous**

From the data gathered for this study, it was evident that considering a broad notion of distress and contentment for all the patients cared for in Almond Ward was a development that may have provided greater gain for many, as opposed to the implementation of a pain assessment tool which would be useful but tackle the needs of a smaller number of patients. From the data already presented in this chapter, it was evident that the notion of distress for PWAD was frequently debated amongst nursing staff but this was in relation to a willingness from nurses to provide an approach to care based on the person, this was identified in the baseline data.

The complexity of identifying the causes of distress, data presented above in section 6.2, also highlighted that a specific problem of pain may be only one source of distress, others exist therefore by adopting a pain assessment tool would only serve to highlight further, a need to understand broader distressed behaviours in the first instance, then focus on the potential presence of pain. Carly and Bessie identified that the DisDAT would provide, 'excellent baseline information.' (Reflection and action meeting, p1, 310506) Their intention was that this would be used for all patients on the ward.

The DisDAT itself, although not designed to identify pain specifically, would assist with an assessment of pain. It would alert staff to a change in the behaviour of a PWAD and initiate further investigation as to the potential cause. It is fair to state that adopting the DisDAT did not ignore the problem of pain and could be regarded as a complimentary process.

*The lady the staff chose to speak about was called Valerie and there was a question mark regarding whether she was in pain, or whether she was distressed. Carly had completed a DisDAT for her prior to the meeting and this helped identify*

*different behaviours, which triggered the thought that she was in some distress and pain.*

(Case review meeting, p1, 200207)

PWAD can clearly experience pain but this can be only one of a number of problems they encounter which cause distress. The data above highlights that the DisDAT was useful in identifying a number of causes of distress, again highlighting the usefulness of adopting a broad stance, before focusing down on one specific problem such as pain.

#### **6.3.6 DisDAT assessments completed by a group of nurses resulted in confidence in the process and high face validity**

*Carly described having completed a couple of the DisDAT's herself and also helping others to complete and having discussions in order for them to complete the DisDAT. Carly described feeling more confident when she does the assessments with others rather than on her own.*

(Notes from Reflection and action meeting, p1, 010207)

A consistent finding from the implementation of the DisDAT was that the confidence in the process was low when nurses completed the assessment independently. Although they had undertaken training and developed guidelines regarding the process of completing the DisDAT, they expressed concern about the subjective elements within the assessment and the consequent validity of the outcomes. Confidence in the process was higher when the assessment was completed by a group of nurses who knew the patient. The factors that increased confidence were gaining varied and broader perspectives that added new information, and the opportunity to debate and validate patient observations and their meaning. Confidence was linked to the perceived accuracy and validity of the completed assessment when undertaken by a group of nurses.

During the planning stages of implementing the DisDAT, nurses had been clear that it would not be possible to hold group discussions to complete the DisDAT due to time constraints, staffing pressures and workload.

*Carly discussed that there could be times during the working day when the DisDAT could be discussed with trained and auxiliary nurses, for example at the end of a shift when staff are together. Carly will ask some of the trained staff how this might be tackled.*

(Notes from reflection and action meeting, p2, 130606)

The above data highlighted how one of the key workers began to practically think about how nurses in Almond Ward could discuss this assessment together. It is evident that this process would be a challenge but a commitment to trying to achieve this is demonstrated.

*Sally informed me she had not completed the DisDAT herself but she was familiar with the information required and the purpose of it. She felt that the DisDAT was an appropriate tool to use when trying to determine if someone is distressed and content and thought that the discussions which staff had together when completing the DisDAT had been useful. Sally felt it was much better if several people completed it as they each had their own perspective to discuss.*

(Notes taken from DisDAT training session, p1, 240407)

Ultimately group discussions did take place as this became the agreed and preferred process following experiences of using the DisDAT. Nurses met together in ad hoc ways and for brief periods as formal prolonged meetings were not possible. Discussions were often staggered, for example two nurses would complete the DisDAT and a further discussion would take place with another nurse who knew the patient well, at a later point. Although these are very practical day to day issues, the researcher would argue that they hold importance in the overall implementation of a process which then had a ripple effect upon the way staff worked. These informal meetings raised issues of inclusion where a range of staff met who had not met together previously to specifically discuss and plan individual care.

These findings are consistent with Regnard et al (2006) evidence regarding the assessment of behaviours of contentment and distress for people with a learning disability. The greater number of people who participate in the assessment the greater the number of behaviours are identified and the more thorough and complete the assessment. The guidelines for using the DisDAT recommend that a group of people who know the patient well should complete the assessment. This research has added to this evidence base in that group

working, involving nurses recognising and agreeing the meaning of behaviours was also felt to be essential within a continuing care context for PWAD. Despite the practical challenges and barriers of completing this as a group, this was the preferred method adopted by nurses.

Within the broader West Lothian Dementia Palliative Care Project a similar finding emerged. In this instance nurses implemented a specific pain assessment tool for PWAD called the Doloplus 2 (Wary et al, 2001). Participating nurses identified that there were elements of this assessment process, which could be interpreted differently by individuals. In order to manage this and aim to have a consistent approach they also determined to meet together to complete the assessment and particularly agree potential areas that could be open to differing interpretation. Group working to complete assessments such as this, particularly those reliant on the observation of behaviour, appears to be necessary and a possible way of tackling potential subjectivity that arises from individuals observing behaviour.

#### **6.3.7 The DisDAT was a useful and appropriate assessment tool for a continuing care setting**

The staff on Almond Ward developed guidelines for use of the DisDAT in their area. A number of key elements in the guidelines related to knowing the person well and completing the assessment over time. The data below highlights these points.

*The patient's key worker (trained nurse) should complete the form but there should be discussion with co-workers or another nurse who knows the patient, it is good to involve the family as well.*

*Anyone completing the assessment should know the patient.*

*On the first occasion the assessment is being completed for a patient the form*

*For a new patient to Almond Ward, the form should not be completed until they have been in the ward for one month.*

(Excerpt taken from Guidelines for using the DisDAT in Almond Ward, p1, 150606)

*It was also evident that this tool needs to be completed over time, in that whilst all of the staff present knew the patient we were discussing, in some ways we struggled to find ways to express her behaviour.....you would need to be conscious of this and go back and forward to complete it (DisDAT) whilst you are working with her and observing her behaviours. We felt that this was important*

*learning and that this patient was well known to all the staff but still we had to debate about what we could describe particular behaviours as being.*  
(Notes from reflection and action meeting, p2, 190606)

Taking into consideration the above data and previous data relating to the complexity of assessing distress for PWAD, it can be argued that this assessment tool would need to be completed in a setting where people are cared for over a period of time, namely many months or years. It is very difficult to envisage that an assessment tool, such as this, could be adopted in a setting where PWAD are present for a short period of time only. The optimum setting may be a service where continuing care is provided and staff have the opportunity to get to know patients over time.

### **6.3.8 Implementing the DisDAT raised expectations amongst staff that the management of distress and pain would be made easier.**

*What have you learnt (if anything)? From having a comprehensive assessment tool in place, assessment is still a challenge. The tool provides a focus, there are less disagreements now regarding the cause of distress. The tool goes a long way to resolve the situation.....Possibly expectations were a bit too high that the assessment tool would solve the problems but clinical judgement is still very much required. It is a most comprehensive tool and has helped with team working and communications.*  
(Notes from final evaluation discussion, p2, 230707)

It is noticeable that the account above highlights the complexity of assessment for this group of people. Even with the presence of a comprehensive assessment tool that has assisted staff with their focus of enquiry, communication and team working, clinical judgement is still very much required and necessary.

*There had been a low response rate to the questionnaire but Carly and Bessie had worked quite hard to promote the questionnaire. There was a desire (from ward staff) for more time to spend with clients; a need for a consistent tool to assess pain, developing activities would also be helpful.*  
(Notes from reflection and action meeting, p4, 180805)

From the onset of this work with Almond Ward, there had been a hope that a consistent tool to assess pain would be implemented. Reflecting on this point, it

is evident that expectations may have been high that this would make the whole process easier.

To conclude it is worth summarising the key messages from the findings and analysis of this chapter. These were:

- The DisDAT, within this dementia care context, provided a person centred approach to assessment
- The term distress, a fundamental component of this assessment process, was found to have different interpretations and meanings for nurses on Almond Ward. Debating and agreeing what distress meant within the context of Almond ward and the patient group was a crucial process in implementing the tool.
- Nurses found working with a broad notion of distress to be advantageous, rather than focusing on a specific problem of pain, potentially missing another cause of distress.
- Completing the DisDAT required the participation of a group of nurses who consistently worked together. In this context the face validity of the tool was felt to be high and nurses expressed confidence in this process.
- The DisDAT was a useful and appropriate assessment tool for a continuing care setting where nurses had time to get to know patients well. Knowing a patient well was a crucial aspect of undertaking this assessment.
- Implementing the DisDAT raised expectations amongst staff that the management of distress and pain would be easier. In reality a completed DisDAT provided robust and comprehensive evidence for treatment decisions. Clinical judgement however was still required and decisions remained difficult, reflecting the complexity of care for PWAD who have severe communication difficulties.

The findings and analysis from this chapter have identified specific outcomes in regard to practically implementing an assessment tool for PWAD that identifies when they are distressed and when they are content. This tool also



incorporates and makes practical, key theories such as person centred care and relationship centred care. It is necessary to consider recommendations, which arise from these findings; these will be discussed in chapter nine.

## **Chapter 7**

### **7.1 Literature Review: Supporting carers (family and friends) of people with a dementia (PWAD)**

#### **7.1.1 Introduction to section**

This section begins with identifying the challenges experienced by carers of PWAD and the impact of being a carer. Literature and evidence relating to the needs of carers is presented in section 7.1.4. Government policies relating to supporting carers are debated and analysed. Effectiveness of carer interventions is then presented and the deficits in research approaches undertaken to evaluate carers' interventions is highlighted. Literature focused on transition to and care within care homes and the impact of this on carers is presented in section 7.1.7. The section finishes with key messages from this literature review (7.1.8)

#### **7.1.2 Challenges for carers of PWAD**

Literature identifies multiple challenges for family carers of people with a dementia (PWAD). In their handbook for carers, the Health Education Board for Scotland (2003) identify and provide guidance for a wide range of issues, which at some stage, carers may have to address. These include:

- Developing a knowledge and understanding of the dementia illness itself,
- Learning to cope with their caring role
- Financial and legal issues
- The practical issues of providing daily care
- Identifying where help can be sought
- Issues related to care within a care home setting.

These are important issues that can have a significant impact on the lives of carers. They involve acquiring new skills and knowledge but also require time, energy, effort and a level of commitment.

It is important to consider that family carers of PWAD may not expect or wish to become a carer. Life is seldom ideal and family members could experience a range of issues, which either inhibit or result in a choice not to become a carer, for example geographical factors, where family members do not live close to the PWAD. Other issues could include other family commitments, their own health problems, financial constraints, previous relationship difficulties with the PWAD and other family members and their own work commitments. The list is potentially extensive and dependent on individual factors.

### **7.1.3 The impact of being a carer**

For those families / individuals who take on a caring role the difficulties and stresses are well documented. 'The manifestations of dementia often cause great physical, emotional and social strain on the lives of family caregivers', (Maas et al, 2004). Brodaty et al (2003) highlights that those family carers of PWAD, experience higher levels of depression and poorer physical health compared to control groups of people who do not provide care. Markowitz et al (2003) investigated health related quality of life for caregivers of people with Alzheimers disease in the United States of America. In a large study (n= 3019) using validated measures (SF-12 short form and a variety of scales measuring disease severity, functioning and utilisation of services) they determined that providing care had an impact on health related quality of life for caregivers. Specifically their sample of caregivers showed that disruptive behaviour and depressive symptoms of people with Alzheimers disease and the volume of time spent caring had a deleterious effect on caregivers. Factors which enhanced caregivers health related quality of life, were increased social support and a reduction in hours of caring. These results appear logical and in keeping with the author's anecdotal experience. It is also significant to note that many family carers of PWAD are elderly and arguably more vulnerable to social isolation and experiencing other normal physical problems of ageing such as arthritis. As our population trends in Scotland show an increasingly elderly population, these results necessitate serious consideration.

Torti et al (2004) in a multinational literature review of caregiver burden, identified similar outcomes, in that behavioural disturbance of the person with a dementia, the intensity of care and co-habitation resulted in an increase in caregiver burden. The authors also identified that female carers bore a heavy burden across cultures and particularly in Asian societies. These results appear logical and would confirm intuitive thoughts about such issues. These authors identified that the degree of burden experienced by carers had a direct impact on the following issues: the time between the acknowledgement of the existence of a problem to presenting at the General Practitioner, the condition of the person at the point of medical presentation and when a person was admitted for long term care. This literature review highlights a direct correlation of the burden felt by carers on the experience of the PWAD. The authors of this paper also highlight some further research findings which are interesting and unexpected: that caregivers adapt to their role over time and the burden reduces, also that the burden is particularly high at the beginning of the disease and subsequently reduces over time. It would appear logical in this instance that once carers know what it is they are dealing with, they can take steps to address and manage the problems experienced. These findings however do not sit comfortably with clinical experience, for example the stress experienced regarding making the decision for a family member to go into long term care and adjusting to this situation. The physical loss of the PWAD as they become terminally ill and die, an emotional sense of loss having occurred sometimes years previously. As a result of these challenges highlighted in the literature, it is necessary to further investigate what interventions carers find useful.

Torti et al (2004) identify that interventions to reduce caregiver burden have been largely unsuccessful but highlight the use of medication given to PWAD as an intervention that reduced caregiver burden. As we will consider later in this section this is a complex issue and the notion of success and caregiver burden has many facets. How is success measured? We will consider how identifying and working towards individual goals for carers is one way of measuring success. This is problematic however in terms of researching outcomes for carers as success may look different for individual carers.

Positive outcomes were however identified from support programmes that involved a variety of approaches and not focused on a single support intervention. A clear finding from Torti et al's (2004) work is the magnitude of the impact of being a carer for a PWAD regardless of geographical area or the society where care is provided.

Bell et al (2001) also discuss the impact of caring on families; there can be adverse physiologic and psychological outcomes for both the caregivers and PWAD. They, like Torti et al (2004), also state a direct correlation between increasing burden on the family carer and admission of the PWAD to a care home or other facility. In this article Bell et al (2001) focuses strongly on the notion of family carer burden in terms of a negative perspective. There is however, no reference to any positive aspects of this caring experience. Health Education Board for Scotland (2003), acknowledge that providing care can be rewarding, 'some people see it as a chance to give back to a parent the care they were given as a child. People with dementia can be calm and happy despite their illness. This could be seen as the Health Education Board for Scotland softening the reality of caring, or deliberately highlighting some positive aspects of caring in their literature. However, anecdotally those who have experienced caring for a PWAD describe periods of laughter, fun and joy, and an honesty of emotion and expression, which was not anticipated. Through the severe difficulties and challenges of the experience, the period of caring can have relevance and significance for the family carer (Killick and Allan, 2001).

A strong emotion experienced by carers can be guilt. Buijssen (2005) devotes a chapter of his book to this issue. Family carers can experience guilt at the point of diagnosis, when an understanding emerges, regarding the recent behaviours of the PWAD. Feelings of guilt can arise as they consider that they should have been more understanding, they should have identified problems sooner and been more active in seeking help and getting a diagnosis. Buijssen (2005: 157) also stated, 'there can be remorse regarding lost time, when more could have been done together, when questions remain unsaid and issues

unresolved.’ During periods when family carers are doing all they can for the PWAD, guilt can still be experienced. Carers can place impossible demands upon themselves, namely that the PWAD must be happy and all their physical needs met, sadly meeting these expectations is not possible and failure is inevitable. Issues of guilt at the stage when a PWAD is admitted to a care home are experienced and will be discussed later.

#### **7.1.4 The needs of carers of PWAD**

The Scottish Executive, (2005) conducted a large research project and prioritised the following actions that would most address the needs of carers, these were:

- Giving unpaid carers a right to regular breaks from caring and providing more and better quality respite options
- Increasing the benefits of people with support needs
- Offering cash payments rather than services so that unpaid carers can arrange care according to needs and preferences
- A greater emphasis on information and training, advocacy and guidance including emotional support.

These needs are unsurprising and follow themes of autonomy, choice and empowerment. It could be argued however that a key concern related to these actions is how older people, unfamiliar with health and social care systems, navigate and utilise cash payments to meet their individual care needs. The principle appears logical and sound but the practical working out of this arrangement is uncertain. Carers can be so engrossed and focused in providing continuous care that there is little energy or motivation left to work through an unfamiliar process such as this. Cultural attitudes towards seeking help and financial assistance will also come into play here, older people potentially muddling on and just getting on with the job at hand, not looking for any ‘handouts’.

The actions stated above do reflect previously established areas of need identified by NHS Health Scotland (2003). They conducted a needs

assessment for dementia and older people. They flagged up the need for the development of respite services for carers, 'with an emphasis on a more flexible approach to meeting needs, and this should mean a significant increase in short breaks of a few hours or more, delivered in a carer's own home,' (p14). A process of Single Shared Assessment would be introduced; this would actively involve service users and carers. The assessment would facilitate access to all community care services and negate the experience of a person, or their carers, repeatedly telling their story to different agencies and that one person would lead the process. Other needs identified for carers were that services should assess risk of carers developing depression and resources should be targeted at those most at risk. Should a needs assessment be carried out for a PWAD one should also be completed for their carer. Carers have a need for information about diagnosis and prognosis and the range of services available to them both locally and nationally. The needs assessment highlights the particular needs of spouses and their potential sense of isolation. In a practical sense carers have identified a need for additional home help support, help with house work, additional help from General Practitioners, additional respite support, sitter services and supervision to help them provide care for the PWAD.

In terms of planning and commissioning of services, NHS Health Scotland (2003) identified the following pathways of care for carers, 'Carer support includes education, counselling, training and respite, with flexible hours of operation (e.g. evening and weekend), availability at short notice, appropriate transport arrangements in small homely, domestic settings or at home' (p52).

NHS Health Scotland (2003) in their needs assessment quoted work from the Dementia Services Development Centre that identified good practice when working with carers. The centre developed these good practice statements from experiences in practice, listening to staff and carers and identifying relevant research findings (p53).

- Carers should be trained, informed and empowered.

- Carers' ability to cope is improved by training in problem solving and stress reduction for carers as well as general information about dementia.
- Carers want diagnostic information and about the services to be provided.
- Carers feel they are experts in the needs and history of the PWAD.
- Carers need to feel respected and part of the care process
- Carers should be involved in service planning and design and evaluation.
- Carers feel cut off but can help when long term care is provided.
- Carers groups are appreciated as sources of information and as opportunities to share feelings but may not be empowered to join the decision making process.
- Planners and managers should consult with carers
- Commissioning staff should work with partner and volunteer agencies to train, inform and empower carers.

It is evident from the research presented and evidence pertaining to supporting carers that commonalities exist in terms of the forms of support carers request. As best practice statements these feel both real and relevant but the challenge is for them to be lived out within care settings and by service providers. Further research is necessary however to consider how this is actually achieved by services.

#### **7.1.5 Government policies regarding supporting carers of PWAD**

Nolan et al (2002) discuss overarching government policies regarding supporting carers of PWAD. The focus has been on a stress / coping paradigm, they argue that many services and interventions have been designed to reduce carer stress enabling further coping and therefore preventing institutional care for the PWAD. A recent focus on community care has in part driven this policy agenda. Within this framework, the objectives of coping and prevention of institutionalisation are therefore the markers of success. A 'hidden' government



agenda perhaps relates to utilising unpaid carers as fully as possible and hence preventing a rise in those PWAD requiring institutional care. Nolan et al (2002), Carradice et al (2003) state that the efficacy of this approach, and the associated interventions, has not been demonstrated and little evidence exists regarding effectiveness. Nolan et al (2002) argues that a shift in approach is required where emphasis is given to understanding the complexities of caring situations and consideration given to what the carer would consider to be successful interventions. This is a highly individualised approach and reliant upon measuring outcomes against in-depth and accurate assessment of the carers needs. Qureshi et al (2000) as cited in Nolan et al (2002) have developed a model, which presents an integrated outcomes approach, namely a process that bases its outcomes on individual objectives derived from comprehensive assessment. The key principles include the following:

- The definition and recording of outcomes should be carer-centred, specific and relevant to the individual concerned.
- The evaluation of outcomes should begin with clarity about the outcomes intended
- Reaching a common understanding of intended outcomes requires a thorough and sensitive assessment
- The carer should be actively engaged as an expert in the process of identifying and reviewing outcomes.

The above principles provide a helpful, structured framework to base assessment upon, but consideration is required regarding methods of evaluation.

Within the last two years a specific carers' assessment has been implemented across Lothian, it is comprehensive in nature, which is in keeping with the principles above, but this would also appear to be a barrier to its use. It is time consuming to complete and practitioners appear to be uncertain as to what to do with the information as the range and availability of services to call on has not changed. Carers who have completed the assessment anecdotally report that in essence it didn't change anything or provide them with further

assistance. Specifically within West Lothian, the base of this research, only a small handful of carers' assessments have been completed and social work staff are trying to develop training and awareness amongst relevant professionals to ensure a wider adoption of this process.

Within a Scottish context, Care 21, the social care innovation unit of the Scottish Executive has recently completed a large-scale piece of research whose aims were to, 'pull together thinking on how the situation for unpaid carers can be improved in Scotland and make recommendations to the Scottish Executive and other agencies as to how this could be achieved' (Scottish Executive, 2005). This multi - method research used household surveys of the general public (n= 2000), postal and web based surveys of carers (n= 4000), a Delphi survey of managers, policy makers and representatives from carer agencies to ascertain their views on the future context of caring namely forces and drivers (n= 1000) and the development of an economic modelling tool identifying population predictions. A steering group, which consisted of stakeholders, directed the project and a large stakeholder event was held where future scenarios were considered and 'robust actions' developed.

The research identified twenty-two recommendations; these followed broad themes such as recognising the rights and needs of carers, shifting control and choice to carers, development of training programmes and involvement of carers in planning and policy making. To develop roles for carers to inspect local providers of carer services and for the UK government to review financial arrangements, which affect carers. A number of the recommendations focused on strengthening carer support networks and ongoing development of government strategy. Immediately after the results of this research were announced, a joint briefing on the Care 21 Project was produced by four Scottish carer agencies. From the names of these organisations it could be argued that there is a need for them to come together with a common purpose and by doing so strengthen their impact on carers issues. The Scottish Carers Alliance, Coalition of Carers in Scotland, Carers Scotland: the voice of carers

and the Princess Royal Trust for carers produced a briefing paper (2005) which applauded the bold vision identified in the recommendations. A positive step in regard to working towards achieving the recommendations of this research was explicit guidance to service providers, regulatory and inspection bodies to incorporate the recommendations into performance management systems. The Scottish Executive has made a commitment to monitor this. A common concern regarding research such as this, is failure to progress to action and that the wide consultation is a politically driven exercise to show interest and concern and to be seen to work in partnership with carers.

The measures stated above, to ground the recommendations into working systems and make responsibilities explicit, might potentially address this concern. The concern however is that the authority to commit to acting upon the recommendations does not solely relate to the Scottish Executive and includes matters, which are not devolved responsibilities. To enable full implementation, the United Kingdom government would require endorsing the reports recommendations, of which there is no guarantee.

#### **7.1.6 Effectiveness of carer interventions**

Within the literature a number of interventions have been identified and used to help family carers look after PWAD who are at home. These have been described above and include a variety of interventions such as education and training programmes, support groups, counselling and breaks from caring (Brodaty et al, 2003). A number of authors have reviewed research relating to the effectiveness of these psychosocial interventions. Brodaty et al (2003) conducted a meta analysis of 30 controlled trials from 1985 to 2001 where the effectiveness of interventions were examined. In reviewing the results of this analysis it is necessary to consider the absence of qualitative data, which could significantly inform real life issues and experiences from the perspectives of carers and also determine future ways of working. The measurements used by Brodaty et al, (2003) included psychological morbidity and burden as well as other outcome measures such as coping skills and social support. The authors judged the quality of the trial by using criteria from the Cochrane database. The

authors highlight the limitations of their findings due to the small number of subjects, low statistical power and that analysis involved multiple statistical comparisons from the same data. They identified that some interventions can make a difference, particularly those whereby the PWAD and the caregiver are involved together, for example teaching problem solving skills. Studies in general showed modest benefit to caregivers for example, improving knowledge, psychological morbidity and coping skills. Interestingly it was reported that carers were either satisfied or very satisfied with the interventions they received. This raises a debate about the perceived success of interventions in terms of professional perspectives and those of carers. An argument is highlighted here between the usefulness of general, standardised measures compared to the impact and usefulness of interventions measured from the perspective of the individual carer.

Carradice et al (2003) are critical of the research methodologies used to investigate the effectiveness of interventions for carers. In particular they argue that research conducted in this area has lacked a theoretical base. Basing future research on existing theories could, 'provide the framework to directing researchers towards beginning to address all the other influential issues,' (Carradice et al, 2003). Improving methodological weakness is a further criticism of past research in this area, use of qualitative approaches, as well as well designed trials are identified as ways of progressing the evidence base. The authors believe that interventions are useful, however the weaknesses described dilute research results and weaken the evidence base. Within this research it would be important to utilise theories such as relationship centred care and person centred care and translate these into the focus of investigating carer support interventions.

Research conducted by Russell et al (1989) to determine the effectiveness of a relative support group, further highlights the difficulties of using global rating scales and the notion of what positively influences the emotional distress of individual carers. The questions they pose in the discussion section of their research highlight these dilemmas. Results from the Beck Depression

Inventory showed that participants had an increase in scores after the intervention. Did a comprehensive understanding of the disease and the implications of being a carer of a PWAD lead to a realistic lowering of mood? Did they realise for the first time that their relative would not recover? As the authors state this research highlights more questions than it provides answers. An individual approach to measuring success of the intervention may have provided a tighter and more useful outcome.

As previously discussed Nolan et al (2002) argues that the effectiveness of carer interventions should be assessed directly in relation to the explicit desired outcome identified by the carer. In summary, the authors stress the following: a move away from professionals being the experts and carers and PWAD setting the agenda, a focus should be to work with people and greater emphasis should be placed on the context of caring. To progress with an evidence base, the authors argue that a clear typology of interventions should be developed providing a common framework for debate, finally the timing of interventions should be evaluated to determine their appropriateness, taking into consideration the context and fragility of the caring situation. As families providing care will remain an important factor in the care of PWAD, taking forward these issues is indeed relevant. Nolan's et al (2002) signposts for evaluating the effectiveness of carer interventions combine a logical approach whilst identifying gaps in current research practices. Their implementation requires a unity of research and clinical practice, which lays down a significant marker for change and evaluation of carer support interventions.

#### **7.1.7 Transition to and care received in a care home.**

In relation to supporting carers of PWAD the experiences of decision-making and transfer to a care home are frequently raised in literature (Davies and Nolan, 2004, Gwyther, 2001, McGarry Logue, 2003, Alzheimer Scotland Action on Dementia, 2004, DeWolf Bosek et al, 2003.) The difficulties experienced regarding the decision to transfer to a care home are particularly highlighted. Buijssen (2005) discusses that decisions are often based on witnessing distress and being unable to alleviate this. Questions exist as to whether to

continue to care and when is the right time to stop. The decision is affected by the emotions of those involved and the tension between addressing the PWAD feelings around the situation and those of the carers. Once the decision has been made and the PWAD is transferred to a care home, a number of authors report that tensions for carers continue. The cessation of caring can turn into worrying and guilt can be constant. The care home's shortfalls and ability to care can become a strong focus for the former carer (Gwyther, 2001). The literature read for this review contained many examples of good practice based on anecdotal accounts and experiential learning. Gwyther (2001) for example discussed actions taken to help carers and PWAD adjust to the transition to a care home. These included acknowledging some of the emotions experienced by the carer and asking them their views as to how staff should best respond to hard questions from their relative, namely requests to go home, and the whereabouts of their partner / spouse.

Davis and Nolan (2004) conducted qualitative research about the experiences of relatives when their family member is admitted to a care home. They conducted 48 semi-structured interviews of relatives who had experienced admission of a close relative to a nursing home. The interviews were analysed inductively, consistent with a constructivist method of data analysis, this involves analysing data as it is collected and developing and using theories to generate new data. The interviews focused on events leading up to admission, the experience of relocation and involvement since admission. During these phases relatives identified key issues, which were classified into themes and were described in the form of a continuum. The themes were:

No pressure → to feeling under pressure,  
Working together → to working apart,  
Feeling supported → to feeling unsupported,  
Being in the know → to working in the dark,  
Being in control → to losing control.

The key messages were that the needs of family members should become a priority and that policies should be reviewed particularly in relation to their degree of user and family friendliness. For the person in the care home, staff should actively acknowledge and support family relationships and draw upon the knowledge and experience of the family carer in terms of the care required by the client. These key findings appear highly relevant but at the same time offer the potential for practical positive changes to practice. The challenge would be for care staff to recognise the usefulness of engaging with families and caring for the person as a whole. For some care homes this may involve a paradigm shift in thinking as the focus of attention can be on work routines, on the resident and family issues may only receive minimal attention.

McGarry Logue (2003) identified barriers in care homes in regard to the concept of 'family as client'. These were identified as:

- Resistance to institutional change,
- Fear and hesitation by family members,
- Institutional rules and protocols,
- Lack of institutional encouragement of family involvement,
- Insufficient staffing,
- Programmes and activities addressing the social and emotional needs of the family and finally
- Ineffective communication between the staff and families.

There are a number of issues stated here, which are common to any change situation within an organisation, namely matters involving communication, motivation and the responsibilities and insight of those who are managers. A potential driver for change could be the possibility that engaging with the family may make caring easier, effective ways of working with a resident could be identified and put into practice.

### **7.1.8 Key messages from literature review: Supporting carers of PWAD**

In summary the following key messages have been taken from the reviewed literature:

- Family carers have a critical role to play in the PWAD experience (e.g. diagnosis, care and support interventions, transition to continuing care)
- Caring can be a stressful and demanding activity where the potential psychological, physical and social impact on carers can be significant.
- Research has identified a growing awareness of the needs of carers and a commonality of approaches / interventions is emerging (e.g. training, flexible breaks from caring)
- Research undertaken into the effectiveness of interventions for carers has been criticised and more effective ways of evaluation is needed. A useful way forward would be to base research on previously identified theory and individually assessed outcomes.
- Partnership and collaboration are key issues both within the research and clinical context. PWAD, service providers and carers being identified as key collaborators.
- Within the continuing care setting, the notion of family as client, and working in partnership with carers, requires acknowledgement and development.
- Although there have been positive governmental and practice developments surrounding the needs and activities available to support carers (single shared assessment, carers assessments, cash payments to carers), the uptake of these initiatives appears to be slow and their impact on supporting carers presently uncertain. Further research is required to investigate the practicalities of supporting carers from the perspective of carers themselves and service providers.

### **7.1.9 Literature review: Where to now?**

The literature reviewed in chapter two has identified that dementia is not widely regarded as a disease that is consistent with a palliative care approach. There are variations in the palliative care provided for people with life limiting conditions and a growing body of research has identified that Dementia care, in



particular, requires development in many areas. Specifically to achieve care that is person centred, manages symptoms effectively and avoids unnecessary interventions. This study will undertake a needs assessment process to gather further evidence of need within the local geographical area of West Lothian.

Research identifies that the assessment and management of pain for PWAD who are unable to self-report is a significant clinical challenge. A range of assessment tools has been developed, however all have strengths and weaknesses and further research is required to determine their effectiveness and use within practice settings. This study will investigate the notion of distress and its relationship with pain for PWAD and how nurses within a community hospital setting, develop their practice within this area of clinical need.

### **7.2.1 Supporting family carers of people with a dementia: findings and analysis**

The findings and analysis presented in this chapter arose from data collected from a day centre for older people, the centre is identified as Meadow Day Centre. In respect of baseline data gathered from this service the results and analysis are described in chapter five, the beliefs and values expressed by staff from Meadow Day Centre, regarding supporting carers of PWAD are also found in chapter five. The day centre was directly involved in the action research project from May 2005 to June 2007, a period of 25 months. Multiple data collection methods were used during the action research at the Day Centre, these are described in detail in chapter four research methodology and methods.

The findings and analysis will be presented in four sections:

#### **7.2 Practice development in carer assessment and support**

- 7.3 Factors that restrict access to support for family carers
- 7.4 Needs of carers are hidden to service providers and remain unmet
- 7.5 Meadow Day Centre's influence on local health and social care dementia services.

### **7.2.1 Practice development in carer assessment and support**

This section will identify how Meadow Day Centre adopted a number of carer assessment practices and support interventions in response to perceived need. The triggers to change practice were: an increased awareness of the experiences of carers and their needs, exposure and response to dementia care training and support from the researcher. The outcomes were a need to provide individual and flexible support to carers rather than group based activities. Adopting a formal assessment tool enhanced understanding of carer needs. The learning that occurred identified a need to focus on the views of carers rather than develop practices based on staff perspectives.

### **7.2.2 The triggers to practice development in carer assessment**

During an action learning meeting held on 22/09/06, the manager of the day centre (Jean) described an approach she made to the centre's management committee.

*Jean started her presentation by talking about the beginnings of a dementia forum at Meadow Day Centre. She had a discussion with the Management Committee of the centre about trying to make dementia care more professional within Meadow Day Centre and focusing on it more. The management committee requested that Jean contact anyone she knew who had an interest and knowledge about dementia and bring people together.*

*(Notes from Action learning meeting, p2, 22/09/06)*

Jean's focus on enhancing dementia care arose from practice development activity initiated by staff themselves, prior to the commencement of this research. They had altered practices during mealtimes, namely reducing noise and stimulation and providing meals for PWAD in a separate environment from

other elderly clients. Information from the Dementia Services Development Centre had provided the evidence for this development. Although no formal evaluation of this initiative had taken place, it had been deemed successful by the staff. They observed improved appetites of PWAD and a reduction in agitated behaviours.

At a reflection and action meeting Jean identified a raised awareness of the needs of carers as a result of early data collection from this research.

*In particular Jean talked about feeling bad that one of the clients no longer comes (to the day centre). He had started to spit repeatedly and this had become quite a problem, therefore he was asked to stop coming and see whether this behaviour settled. When this gentleman's niece gave her perspective in the interview Jean felt bad. This decision was made quite quickly, not sure how much consultation ensued or attempts to try alternative ways of managing.*

(Notes from reflection and action meeting, p1, 151105)

During an interview the researcher had with a family carer as part of the baseline data collection, it was evident that there was very little support for this man and his family, and Meadow Day Centre had provided useful support in terms of respite for the family. When the above data was fed back to Jean and Tam (dementia care support worker) they were concerned they had excluded this client prematurely, without exploring behaviour management approaches.

From this data and other experiences there was a sense that they could, when suitably focused, successfully change their practice and implement activities, which had a positive impact for PWAD (for example changes to meal time practices). Staff described this practice development experience as building up their confidence.

Feed back from families although positive, had concerned Jean and Tam. They had not appreciated how much their service was both needed and valued by families. Family carers also reported a lack of local alternative services available for PWAD and their carers. This above data pointed to a sense of guilt and lack of professionalism felt by the staff. They were concerned they had not considered options of working with the client who had a problem with spitting

rather than decide he could no longer attend. This acted as a trigger for them to explore ways of enhancing support to carers in the future. This data also highlighted to the staff the scarcity of services for PWAD in their area and that they had something valuable to offer. The knowledge of minimal service provision within their area was not new to the staff, but the concept of their service being perceived as playing a valuable role for family carers had been enlightening and a positive reinforcement of their work.

*'They (family carers) were really pleased with the service and felt it was valuable. The main value identified was that their relative socialised with others and felt that they were safe. They also valued keeping communication open and knowing that problems would be discussed'*

(Notes from reflection and action meeting, 170805)

At a reflection and action meeting on 170805, I reflected however on Jean's sense that Meadow Day Centre was on the fringe of other services, and unable to participate effectively.

*'The staff feel that Meadow Day Centre is on the fringe of services which provide dementia care and that their input and potential input is marginalized. This leads to a situation where they are keen to participate on a wider stage and influence what happens both for the individual clients and with regard to dementia care in general, (example having recently set up a dementia strategy group). They are keen to work with other services within this project and see this as very positive.'*

It is evident from this reflection that Meadow Day Centre could see a bigger picture of need for PWAD and their carers however there was a sense of disconnection of local services that negatively impacted on the experience of clients. These findings will be discussed further in section 7.3.

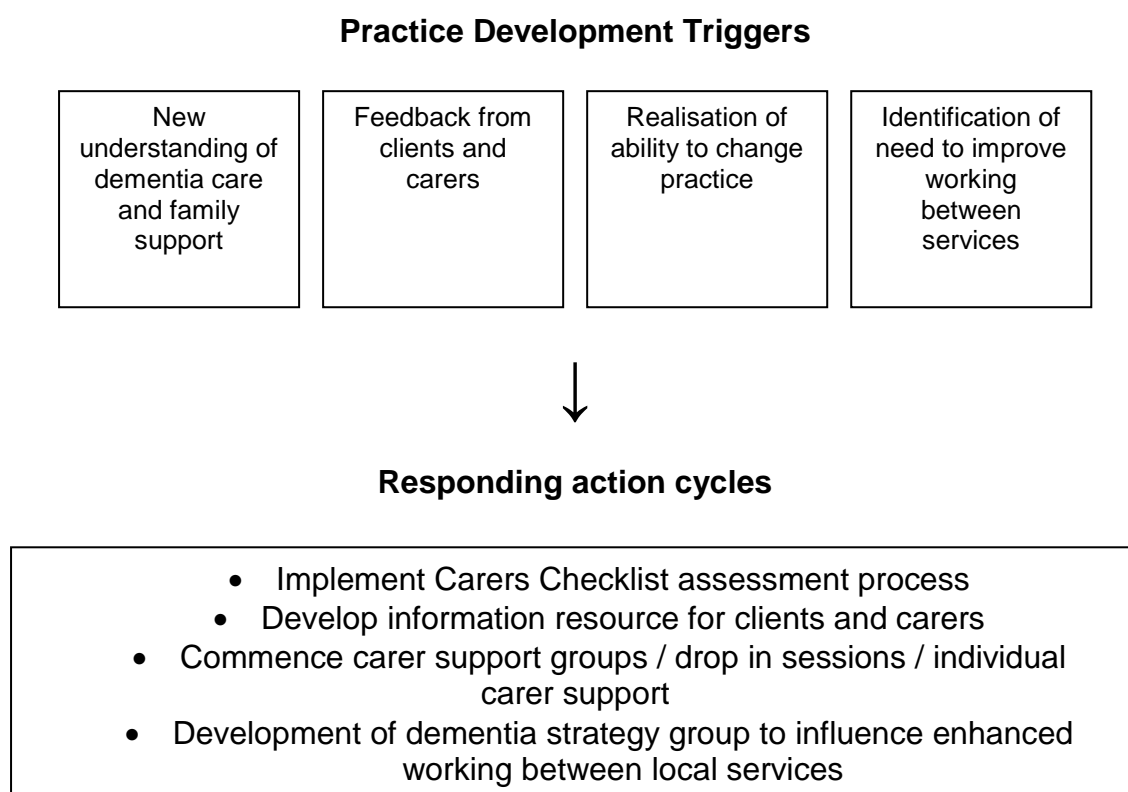
### **7.2.3 Dementia care training: a trigger for practice development**

Dementia care training sessions held in May 2006 acted as a further trigger to developing carer support interventions. Staff from the service participated in two specific sessions regarding the experience of and support needed by carers. Jean (Manager) wrote the following comments in a report to local dementia services and the day centre management committee. The purpose of the report was to highlight the action research and development work taking place at the day centre.

*One of the training evaluation questions was, how do you think you can use what you have learnt from today's training? Some of the answers are detailed below: Empathise with a carer's situation more confidently, give information to assist them and direct them to other agencies....Keep working on being more observant of people who have a dementia and their carers.*  
(Jean's report, 010806).

The staff from Meadow Day Centre had not previously undertaken collective training in dementia care. Tam (Dementia support worker) had experienced dementia training of an ad hoc nature but not to a similar extent or depth. The training had instilled a common sense of understanding and purpose, although at this point, the specific carer support interventions to be taken had not been identified.

To summarise the triggers that initiated practice development activity were: a collective new knowledge and understanding of dementia care, positive feedback from carers who used the service, an awareness that they had the ability to positively change and develop their dementia care practices, and the identification of a bigger picture of need within their local situation. The triggers for practice development and consequent action cycles are represented in Figure \*6\*



## Figure \*\* Practice development triggers and action cycles

These triggers are consistent with practice development theories identified by NHS Education for Scotland (2006). They identified that practice developments are initiated from three broad sources – educational and credentialing drivers, policy drivers and practice drivers. It is evident that the drivers from Meadow Day Centre arose primarily from education and practice.

During the conduct of the action cycles identified above in figure \*\*, an in-depth case study was conducted with a client and family carer from Meadow Day Centre. This case study reinforced new understandings and highlighted further needs of PWAD and their carers. The learning from this case study strongly influenced the action cycle focused on enhancing joint working between local services in West Lothian.

### **7.2.3 The outcomes of practice development activity in carer assessment**

The main activity in regard to the assessment of carers was a decision by Jean and Tam, in conjunction with the staff from the day centre, to implement the Carers' Checklist (The Mental Health Foundation, 1998) Appendix 22. The researcher, whilst reviewing the literature about assessing carers of PWAD, had identified this assessment tool. The aims of adopting this tool were agreed as identifying and including the carer's needs as part of the client's initial assessment process, and within the scope of the Day Centre's service, respond to the carer's individual needs.

Implementation of the tool involved the staff deciding how it was to be used and a pilot of its use amongst staff and volunteers. They decided to use it during the client's initial assessment, when the referred person would be visited in their home. They wanted to ask the questions rather than the carer complete it independently. This would involve a dialogue where concerns could be explored further and it also provided an early opportunity to develop a positive

relationship between staff and carer. The staff made a number of other practical decisions regarding its use.

At a reflection and action meeting (100506) Jean and Tam discussed the need for tact and sensitivity when using the tool. Some of the questions could be difficult for the carer to answer and they were particularly worried that the carer may think they are going to experience all of the problems identified in the checklist. This would be an extreme scenario but could potentially cause a carer unnecessary concern.

The following notes from reflection and action meeting (210806) identified Tam's initial experiences of using the checklist.

*Tam described one carer who felt that stressful was quite a strong word in the questionnaire and they wanted to change it. Tam described trying to individualise the questionnaire by writing words and phrases used by the carer, as well as ticking the boxes. They had used the process of reading out the questions and then filling it in for the carer. Tam described that when asking questions, you would generally get a story but this was important in the overall understanding and connection made with the carer.....Tam's initial feeling, having completed two questionnaires were positive. You got a feeling of what was going on, you felt that you knew more about the client than you had known before and that the two carers interviewed had been positive, as they were trying to help the client as much as possible. Tam sometimes felt that the carers were pushing the clients out of the door which is distressing'.*

It was evident from the collection of the baseline data described in chapter 5, that Tam valued exposure to assessment tools and different ways of working. In the past, he had received only minimal and infrequent training in dementia care, although at the time of the research he was undertaking a Scottish Vocational Qualification in care. He relished new ideas and ways of working, the stimulus of doing something differently appeared to be refreshing to him, as much of his work appeared routine. He was very positive about the use of the checklist, but it is necessary to consider this in the context of an absence of a previous formal assessment of carer need and therefore he had little comparative experience. Tam's focus on developing a useful relationship and connection with the carers by engaging in dialogue, identified a positive attitude being acted out in practice. Similarly Tam expressed concern with past

situations where he felt that family carers had sent the PWAD to Meadow Day centre to give them some peace, regardless of any potential benefit or harm the client may experience.

During the final audit of documentation (240707) a number of challenges had emerged in terms of using the Carers Checklist. When the staff from Meadow Day Centre went to the home of the potential client there appeared to be a pressure of time instigated by the carer, staff consequently felt on these occasions, it was not feasible to complete the checklist in full. Potential reasons for this were felt to be due to clients and carers not expecting such a thorough assessment to take place from day centre staff, an awkwardness about discussing their problems and asking for help from the day centre. There were occasions when the carer expressed discomfort answering some specific questions in the presence of the PWAD.

There was a need for Meadow Day Centre staff to be sensitive to the reactions of the carer. When conducting the initial assessment at the home of the referred person, there was a need to be flexible and respond to the situation at hand. Two people from the day centre completed the assessment one concentrating on the PWAD and the other on the carer. Within the person's home situation, it was necessary to take the lead from the clients as to how to conduct the assessment.

It was positive that the Meadow Day Care staff discussed a need to be sensitive and responsive to individual situations. This highlights that although the tool was felt to be appropriate and valid, ways of using it required exploration and reflection. Through an audit of documentation (240707), alternative approaches to conducting the assessment were explored and agreed. Within this data it is evident that the day care staff were receptive to exploring and reflecting on practice, however they needed the experience and facilitation of the researcher to jointly conduct the audit. Their sense of disconnection with other services, coupled with a lack of engagement in previous practice development and low level monitoring of the service by West



Lothian Council, were factors identified as detrimental to developing the care of clients with a dementia and ways of supporting their family carers at Meadow day Centre.

#### **7.2.4 The learning experience of practice development activity in carer assessment**

Participating in this action research project had filled an expressed need identified by the service to enhance their care for PWAD and their family carers.

*'The staff at Meadow Day Centre have given minimal consideration as to how they record their assessment and planning of care for PWAD. I have been surprised at the absence of this sort of work and that little attention has been given to more formal processes of assessing and planning. Less stringent external evaluation of the service could be a factor in this but also that the service is predominantly for older people and not a specialist dementia service. ....There is a recognition from Jean and Tam that this is something that needs reviewed if a professional service for PWAD and families is to be provided and they are currently reviewing this, an action spiral which has come from baseline data collection activities.'*  
(Reflection notes, baseline data feedback discussion, 170805).

During our final evaluation discussion of the project on 240707, Jean and Tam identified a key aspect of learning from this process.

*We use the carer's questionnaire and that has made a big difference and that way we have a much better insight into the carers and their situation at the time of completing the report. There is now time set aside during the assessment process to focus on the carer, as well as the person who has been referred to day care.*

The use of a formal assessment tool had increased awareness and understanding of carer's experiences and needs, this was viewed as a positive outcome. This assessment process demonstrates a practical application of NHS Health Scotland's (2003) good practice when working with carers. Acknowledging the expert nature of carer's knowledge about the needs and history of the PWAD, giving respect and being part of the care process, and the need for carers to have information about services provided to the PWAD. Implementing a formal carer assessment, such as The Carer's Checklist (The Mental Health Foundation, 1998), was also consistent with providing support to carers in respect of key challenges they will experience, for example learning to

cope with the caring role, including the practical issues of providing daily care (Health Educations Board for Scotland, 2003).

Section 7.5 describes how a greater understanding of carer needs motivated Jean (Manager) to undertake further development activities external to the day centre.

### **7.3 Factors that restrict access to support for family carers**

In this section findings related to the restrictions, experienced by carers when attempting to access support, will be presented and analysed. Key findings included the following:

- The ongoing provision of care for the PWAD took precedence over carer needs and wishes to engage in support activities.
- The physical and psychological affects of caring, negatively impacted on the motivation and ability of carers to participate in support activities.
- The principle of group-based support was welcomed but did not prove a practical option for the small group of carers connected to Meadow Day Centre. Individual and flexible support options were preferred and proved viable.
- The behaviour and preferences of the PWAD became key factors in the services available to carers, consequently having further impact in terms of access to support.

#### **Planned carer support interventions at Meadow Day Centre**

Following completion of two preliminary action research phases, namely developing a baseline understanding of the service and then conducting a beliefs and values clarification exercise with the staff and volunteers, carer support interventions were agreed, planned then implemented.

The interventions included a carer support group to be held every three months, a monthly drop in carer support session and individual support from Tam, the Dementia Care Support Worker. The respective aims of these

interventions were: for carers to receive support from other carers through facilitated group discussion; provide a point of contact between carer and day care staff; provide an opportunity for individual support (listening, provision of information and finding practical ways of addressing problems). The provision of a range of support interventions for carers was consistent with Torti et al's (2004) research findings that carers found this more beneficial than a single support intervention.

The day centre were proactive in their planning and provided care for their clients (PWAD) during the support group and the drop in session to give as comprehensive a service as possible. The staff also developed their information resources and specifically offered opportunities to review dementia / carer information with carers. They undertook a variety of strategies to enhance carer access to a wide range of information. Collectively these interventions were consistent with approaches promoted by NHS Health Scotland (2003), as responsive to the identified needs of carers.

### **7.3.1 The impact of continuous care giving**

One of the data collection approaches used to identify carer support issues and evaluate the impact of interventions, was a case study approach. This involved working alongside a client (John) who had a dementia, using participant observation. Interviews with the main family carer, John's wife Dillis were conducted before and after the period of observation. Throughout this data collection activity, a process of feeding back and analysing data with the day centre staff and the main carer took place. The client identified by this service, and the case study that took place, highlight a number of key issues, which will be presented in this section. The author of this paper would argue that the case study is representative of the experiences of carers of PWAD.

During the first interview Dillis (carer) highlighted key aspects of care she provided for her husband.

*'Dillis stated that one of the main issues was monitoring his clothes. He would get dressed in the morning and then he would put on extra layers of clothes, clothes that were inappropriate for him. He had put his wife's trousers on this morning and also he would put on clothes that are in the laundry basket for washing. This needs continual monitoring and getting him to take off layers of clothes if he is getting too hot.....Dillis described that he does not realise things are what they are. Dillis gave the example of cigarette lighters, he will stand with two lighters in his hands and say is this all the cigarettes I have? He has a thing about trying to light cigarette lighters, using one to light the other one and he needs careful monitoring.....DC described an incident the other day when early in the morning she would not get out of her bed at about 5am and John stood at the side of the bed and screamed at her, asking her to get up and get out of bed.'*  
(Interview with Dillis, 280906)

It is evident from the above data that monitoring and managing his dressing activity was an ongoing task. There were also significant risks that required careful and continuous monitoring, particularly in relation to smoking. Other aspects of care described by Dillis were: restlessness at night, safety hazards in the kitchen, for example putting metal pots in the microwave and John making continual references to his mother and children which pointed to his reality being set in a time frame approximately thirty years ago. It is clear that the cumulative nature of these caring activities represented significant and arduous demands upon Dillis.

To further compound these caring responsibilities, Dillis suffered from emphysema and at the time of our first interview was recovering from an episode of painful shingles. Going up and down stairs and frequently checking on her husband in regard to his repetitive pattern of changing clothes, made her breathing problems worse. Combined with a significant lack of sleep, these appeared to be the most significant physical problems she encountered.

*Dillis described the fact that if she was fit and well, these things would not be too much of a problem, but she does have difficulty with her breathing and running up and down stairs can make her out of puff and she struggles with that. Dillis described how difficult it was and that he can spend all day wandering around and changing clothes and it can be very difficult and frustrating to be in the house with him whilst he is doing these things, especially on an ongoing basis, day by day. Dillis felt that it is sometimes very frustrating and it can drive her mad, having to deal with this each day.*  
(First interview with Dillis, 280906)

Later on during this first interview, Dillis' daughter intervened when we began to speak about the impact of this caring.

*Dillis also, with prompting from her daughter discussed having shingles and that this could be related to her feeling a bit run down, tired and generally low. Dillis' daughter also felt that she got low in mood and a bit down and Dillis agreed with her that she does get depressed at times with their current situation and there are times when she gets really upset and emotional. Dillis' daughter felt that she also got a bit negative about things and Dillis asked the question, do I? And then she made a comment that her daughter can provide more information than she can about the impact on her caring for her husband. SS suggested that it could be the ongoing monitoring and managing of the situation that is difficult and Dillis agreed with this – she said it is not something during the day or night, it is the 24 hour issue that makes it so very difficult.*

(First interview with Dillis, 280906)

From my initial interview with Dillis these care issues seemed to involve significant physical and mental effort. What was difficult to comprehend was the ongoing nature of her caring. Her husband's behaviours were not present every day, nor were they of a severe nature every day, however Dillis had the responsibility to respond to them in whatever form they presented. From my own experience, there are many families for whom this level of caring, and the physical and mental consequences involved would have proved to be impossible, and the PWAD would have, by necessity, been admitted to a continuing care setting. The Health Education Board for Scotland (2003) identified that carers have to address an extensive range of issues which can be daunting and entirely based on individual factors, such as the presence of family who are able to help.

The physical and psychological impact of providing this intensity of care over time resulted in Dillis not accessing the carer support group or the drop in sessions held at Meadow Day centre.

*Dillis spoke about the help offered by Meadow Day Centre and spoke about the drop in session....but she highlighted the difficulty of leaving him (John her husband) and that is a problem for her. Dillis also spoke about the evening meeting (carer group) .....she had shingles and was unable to go, they even provided care for John at that (carers group). ...Dillis emphasised that evenings can be difficult, it can be difficult to motivate yourself.*

(Interview with carer, p5, 280906)

For a variety of reasons she prioritised John's needs over her own. These findings are entirely consistent with Maas et al (2004) and Brodaty et al (2003)

who identified higher levels of depression and poorer physical health for carers of PWAD. Within the context of this case study, these difficulties persisted and were largely unresolved by those services involved in supporting Dillis.

A further issue which impacted on Dillis' continuous care giving was that his own family did not live locally. He had two children from a previous marriage, a daughter who lived in Ireland and a son in England. He was too severe in his dementia to stay with them, a further lost opportunity of respite for Dillis. His daughter visited regularly and Dillis regarded her as helpful and aware of the situation. The son visited very infrequently and Dillis described him as being in denial, not coping with his father's deteriorating situation therefore choosing to avoid it. The outcome of this family situation meant that Dillis carried the ongoing practical responsibilities of caring. She had a daughter of her own, John's stepdaughter, who was helpful and took on the role of supporting both her mother and John.

### **7.3.2 The behaviour and responses of the PWAD impact on carer access to support**

Data from the case study identified that the response of the PWAD to services had a direct impact on respite and breaks from caring for the carer. During her first interview on 280906, Dillis highlighted that her husband had attended a day hospital for a short period but this intervention had been unsuccessful.

*John had gone to the \*\*\*\*\* Day Hospital but had really hated it. He found it a depressing, miserable place and he could not stand to go there any longer. Dillis described that the day centre was a most unpleasant experience, people sat like zombies and there was only one gentleman who spoke to John.*  
(First interview with carer, p5, 280906)

Due to this negative experience, Dillis as a consequence had missed out on valuable respite time and the loss of a process of ongoing assessment from a healthcare team based within a day hospital. Positively however John enjoyed his visits to Meadow Day centre and was relaxed and happy to attend.

*'Dillis was really positive about Meadow Day centre, she thought they were great and really approachable and that she would be comfortable about approaching*

*them as opposed to her own GP. She felt the staff were really nice with the clients and she was able to see this for herself as she attended with John initially. Dillis also felt that the staff did understand what help she might need or want, but the bigger question is whether she can get help or not, that might be out of the day centre's abilities.'*

(First interview with DC, 280906)

Throughout this action research, multiple data has been gathered which reinforces this issue. As the PWAD deteriorates and their behaviour becomes more challenging, the main carer becomes increasingly isolated and the input of professional support takes on greater significance. Professional support in terms of those people who have specific roles within dementia care, for example psychiatrists, community psychiatric nurses for the elderly (CPNE) and social workers. The more severe the degree of dementia, the less generic services are available to provide options of support and respite. Within the needs assessment data presented in chapter three, it was evident that for some carers this increased responsibility and isolation had significant consequences, such as alcohol dependence, financial difficulty and depression. Again these findings are consistent with research about carer experiences and the need to strengthen carer support networks (Scottish Executive, 2005).

Another factor that impacted on the support or help available to Dillis was her husband's suspicion of anyone he did not know being in their home.

*The next question was about what help Dallas might want or what would be useful to her. There is an issue here that Jim does not like people coming into the house....unless she (Dillis) was present.*

(First interview with DC, p6, 280906)

This meant that support options available within the home were restricted. I witnessed this at first hand when conducting the initial interview with Dillis at their home, during which time her husband returned from the day centre. John was clearly suspicious of me but on this occasion there were no problems. Dillis appeared apprehensive and agitated, concerned about her husband's potential response. From being initially relaxed and talkative, when John returned home she appeared tense and preoccupied. The interview came to an end quickly. There was a combination of problems evident in this situation, John's consistent suspicion of strangers when in his home, resulting in challenging

behaviour. Dillis' anticipation and anxiety in regard to John's potentially difficult response to this situation also requires acknowledgement. It is easy to identify how this scenario would compound problems of isolation, as people would cease visiting the couple due to the expectation of a negative response from John and fearing they would precipitate undue anxiety and stress for Dillis.

### **7.3.3 Preference of individual and flexible carer support options**

The group format of carer support interventions described above, required a degree of consideration and planning on the part of the staff. There was considerable disappointment, when after three carer support meetings and four carer drop in sessions, no carers had turned up to any of these interventions. All of the staff of the day centre had been involved and were available during these sessions to care for PWAD whilst the carer met with staff, therefore these interventions were both financially costly and time consuming. The staff had updated and organised their information and gone to the extent of advertising the sessions in the local newspaper when the initial meetings had failed to achieve a response. They had also made direct contact and given invitations to those carers who had family members that were clients of the centre.

The staff debated the reasons for non-attendance and there was direct evidence from the small number of carers who may have accessed the service, that the practicalities of caring took priority over attending. It was known that some carers did not seek support from anyone, repeatedly blocking attempts made by services to offer help. Other carers stated the support they already received from Meadow day centre was both valuable and accessible.

*'Generally I feel I can talk to any of the staff here and also that they would speak to me if they had any concerns. One example was when my husband became agitated at one of the other men who attends Meadow Day Centre, he was singing partisan songs and he thought this wasn't right and it was offensive. He told me he asked the man not to sing these songs and felt he should take some responsibility for this. Tam came and spoke to me about it. He told me about the problem and that they were trying to help the man in question and he wasn't attending for a wee while. He kept me informed which was good'.*

(Interview with carer, 120705)



As the above extract from a carer interview highlights, it is feasible that the perceived level of carer support from staff at the centre was good, flexible and already available. My contact and evidence gathered from carers I met during the research period at Meadow Day Centre, identified similar positive responses. The centre is small and a friendly atmosphere prevails, regular contact with carers takes place, in some instances, on a daily basis when clients arrived and went home.

During a final evaluation discussion with Jean and Tam held on 24/07/07, the key workers described their views about the attempts to provide group support. In response to the question, what did you think was difficult or challenging?

*Getting the carers support things right. It was worth trying the carer support groups and the one to one drop in sessions. It was a process that was useful but it was difficult to get that right. It was quite demoralising to have worked hard in setting these things up and for them not to be used. With hindsight, we perhaps tried too hard to engage carers without checking what their expectations of the centre were.*  
(Final evaluation, p4, 24/07/07)

From the commencement of work at Meadow Day Centre particularly considering baseline data collection as described in chapter five, the staff have made decisions and taken actions in a very autonomous way. They have a 'muck in approach' where everyone gets involved and they change their practices with little consultation. There is a flat management structure and little evidence of decisions having to go through a hierarchy. In terms of the attempted group based carer support activities, it could be argued that they followed their usual pattern of changing practice with minimal consultation. From my own reflections I challenged myself as I was aware of their quick decision making patterns but however we still pursued this approach. My learning and awareness had not taken into consideration the small sample of carers we were drawing from and the perception that Meadow Day Centre's main provision was as a social setting for clients and did not have an overt or perceived role in carer support. They were keen to develop support for carers due to their increasing awareness and understanding of the experiences and significant challenges carers experience.

Following reflection and review of carer support interventions the staff opted to follow an individual approach to carer support, however should the carers change they intended to review this.

*What did you think was difficult or challenging? Trying to get the carer support in place. I feel we now have appropriate support in place for our carers. With hindsight we perhaps tried too hard to engage carers without checking out what their expectation of the centre was.....It was quite demoralising to have worked hard in setting these things up (carer support groups / interventions) and for them not to be used.*

(Final evaluation, p4, 240707)

Following an individual approach had key strengths, it utilises information from the Carer's Checklist and directly shifts the attention to the carer and identifies from a range of options what support would be useful to them. Examples of individual carer support include the use of client diaries as a two way communication aid and regular telephone calls to carers to assess their situation, asking the carer if they have any concerns or questions and updating them on the PWAD and their time at the day centre.

#### **7.4 Factors that result in the needs of carers being hidden to service providers**

In this section key findings will be presented which identify that the needs of carers were hidden. Specifically that services for PWAD in West Lothian were disconnected resulting in ineffective information sharing and referral processes. There was no evidence of ongoing, 'live' access to professionals to guide and support carers. The data gathered during the case study, identified that the PWAD had an effective social façade which acted as a further barrier to service providers understanding and responding to the family carer's needs.

##### **7.4.1 The social façade of PWAD leads to hidden disability resulting in unidentified and unmet carer need**

A key theme to emerge from the four periods of participant observation conducted with John at the day centre, was how difficult it was to understand the level of disability he had and, as a result, the needs of his carer, his wife were hidden to the day care staff and other service providers.

During the participant observation, I recorded many observations, which focused on the social facade John presented whilst at the day care setting. In terms of his appearance and the way he conducted himself, there was nothing out of the ordinary. Despite my awareness of his behaviours regarding putting on many layers of clothes, each time I saw him he arrived at day care looking presentable. He is small in stature and very nimble on his feet, quite surprisingly so, he could walk very quickly and he leapt on to the mini bus without the use of the steps, a feat which impressed all those who witnessed it. Within group activities he sat on the sidelines, actively not taking part but looking interested or commenting on the proceedings. When I spoke with him it was evident that, at a superficial level, he could take part in a conversation, but when questions became more in depth he was unable to respond and the extent of his disability became evident. I observed that he actively avoided these situations, as if he knew he might be found out or people would see he was struggling. He would avoid this by going for a walk in the garden or positioning himself on the 'sidelines' of a group.

The following extract from participant observation highlights a situation where other clients were surprised by his behaviour and evident disability.

*After a period of time he (John) went out for a cigarette but it was rainy and cold and he went into the shed area in the garden, where they are allowed to smoke. I went with him to make sure he was all right and watch him light his cigarette, but he took a comb out of his pocket and his lighter and he began to light the end of the plastic comb, thinking the comb was a cigarette. When I informed him of what he was doing he stopped and looked for his cigarettes and managed to light a cigarette. The other people (clients) who were smoking in the shed looked quite surprised by what he had done and I think this fits with the social façade he gives, that everything is all right and he looks relaxed and comfortable but it very much masks the disability he has.*

(Notes from participant observation, p1, 161106)

The following data was taken from a discussion that took place during a period of participant observation. We were looking at pictures of John's family, which his wife had provided. The aim of this activity was to provide a means for John to express any thoughts he had about his wife, their current situation and the care she provided for him.

*The picture he responded to the most was of his daughter. It was quite a large picture in a frame, black and white and looked as though it was taken in the 1960's, a very attractive lady, he kept looking at it and referring to it. It was interesting that he kept looking at it, and spoke in a surprised way as if he had not seen it only a minute or two earlier. It was obvious that his memory of what he had seen in the last two or three minutes was no longer there.*

(Notes from participant observation, p2, 161106)

This data, in quite a stark way, identified John's significant memory loss. My own reflection on this was one of surprise. I had not expected him to have such severe memory loss, and I had been in the privileged position of gaining an in-depth understanding of his situation from his wife and service providers, but also from working directly along side him in the day centre. The key point being how could those service providers with only brief contact with John understand his degree of disability, when I, who had significant contact and understanding of his situation, was surprised at the severity of his problems. This issue applies particularly to providers such as General Practitioners who have the essential role of engaging with services for PWAD and their carers, but potentially see patients only for a brief period. The day centre staff were also not aware of the severity of his problems until it was highlighted, this was the service that had the most knowledge about him. It is logical that as a result of this misunderstanding of John's needs, this would directly result in consequent unmet need for his wife, his main carer. The significant difficulties highlighted in this data, in regard to assessing John and understanding both his needs and the needs of the carer, point towards the benefits of adopting a relationship approach to assessment and care (Tresolini and the Pew-Fetzer Task Force, 1994). In light of the data presented above, the challenge of a generic health professional, for example a General Practitioner, meeting John and accurately assessing his problems and the needs of his carer would be most unlikely. Within the context of a relationship between the GP and John and his wife, the challenges and complexity of the caring situation would more likely be understood and, as a consequence, supportive measures introduced.

John had a very quick-witted sense of humour, which he used to his advantage in social circumstances. There were many occasions where I reflected on my

surprise at this ability. He would make a throw away comment which was appropriate to what was being said and involved a sense of timing and understanding.

*When I arrived at the day centre, John was sitting with all the other clients, looking relaxed and comfortable, legs crossed, smiling and laughing with various people around him, he did not really engage in any particular conversation.....the television was on and adverts for the new James Bond film came on, there was general discussion about this and people reminiscing about past Bond films. With encouragement John joined in the conversation and made a quick witted comment about him being the next James Bond! A clear sense of humour came through...jovial and quick witted.*

(Notes from participant observation, p1, 161106)

This was what the other clients of the day centre witnessed and understood about John. When discussing this with his wife and stepdaughter they both identified that this was his style, very funny with quick, witty comments, which had a sarcastic slant, and this was what I had observed. In terms of appearance and brief conversations, there was nothing about John that would arouse a suspicion of any problem.

Any questions I asked him in relation to his short term memory he was unable to answer, he would not know what day it was or where he was. He had ways of getting round this however and would laugh something off or make a joke of not knowing the answer, for example he would say, oh now that's a hard one to answer, or you'll need to let me think about that. Predictably he was able to engage in telling you about events from the distant past although his stories were brief as he struggled to find words to express himself.

I observed him concentrating very hard in regard to using cutlery at meal times. The impression was that he was very aware of his social situation and the need to manage independently and use a knife and a fork. He seemed to blend into the group and avoid one to one contact and discussions as if aware of his problems and either consciously or subconsciously actively managing them by avoidance.

When feeding back my observations to the day centre staff and to his wife, there was acknowledgement and agreement that his needs were hidden, even to the day care service that were actively involved in his care. As a logical consequence of this, the support required by his wife and her needs, as his main carer, were also hidden.

*There was some laughter as the staff read some of them (notes from participant observation). Jean, after finishing reading the first one said it made her feel quite sad when you had an insight into what someone's life is like and all the difficulties that are there for them now. ....Tam having read the notes felt they reflected what he saw and his knowledge of the situation. CB (Social work student) was taken with the amount of effort that is involved in keeping up with appearances or to looking like he (JC) is on top of things and knowing what he is saying or doing. (Reflection and action meeting, 051206)*

During the second and final interview with Dillis, the issue of maintaining a social façade and the impact of this was discussed. The purpose of this interview was to review the data from the participant observation conducted with John and discuss the emerging findings.

*Stephen spoke of the social façade when he (John) is in a social situation in day care and that he really has to work hard to appear in control of things and that for example, at the meal table using cutlery and eating his food and also his general behaviour. Stephen sensed that in some ways it appeared quite a strain for him to look like things were all right. This was also an important issue in regards to finding support for Dillis, that he himself gives very little away and his problems are not evident and therefore are also not evident with regard to Dillis' (wife) needs in the care that she provides for him. Dillis and her daughter very much agreed with these comments.....Stephen also talked of the sense of a boundary, where he could ask John questions and discuss things with him, but there was a sense where he would need to stop and he did not like to be pushed or questioned too much as he found it uncomfortable. Particularly in light of wanting to look like he was in control of things, there was also an element of being private but also not wanting to be shown up for not understanding or not having things right in his head. Dillis (wife) and her daughter very much agreed with this and stated this was real as to how he behaved and how he responded at home. (Second interview with Dillis, p3 , 300107)*

The significant difficulties highlighted in this data, in regard to assessing John and understanding both his needs and the needs of the carer, point towards the benefits of adopting a relationship approach to assessment and care (Tresolini and the Pew-Fetzer Task Force, 1994). In light of the data presented above, the challenge of a generic health professional, for example a General

Practitioner, meeting John and accurately assessing his problems and the needs of his carer would be unlikely. Within the context of a relationship between the GP and John and his wife, the challenges and complexity of the caring situation would more likely be understood, and as a consequence, supportive measures could be introduced.

#### **7.4.2 The absence of ongoing, 'live' access to professionals, had a negative impact on carer support**

The following data is taken from reflective notes following the first interview with Dillis, wife of John.

*As the interview progressed, I was aware I became very concerned about the few services she (Dillis) was receiving and how difficult things were for her. Her own health and psychological status was deteriorating. She was receiving no ongoing support other than from Meadow Day Centre, two days a week respite. On reflection about this I felt I would discuss this with the staff from the day centre, during the consent process she was happy for the information to be shared with the day centre staff.....When I left the house I felt bewildered as to how she coped with each day, no wonder she was feeling low in mood and negative about things.*  
(Notes from reflection of interview with Dillis, 280906)

From my own experiences in practice of care for people with cancer and those in receipt of palliative cancer care services, a person with an equivalent advanced stage of disease such as John had, would be receiving an array of services and benefits from both specialist and generic services. I was conscious of my sense of bewilderment that John had no live contact with professionals responsible for care for PWAD other than the service provided by Meadow Day Centre. All the more notable, in that the family had initiated the involvement with the centre, as they had undertaken a self-referral process. This very starkly highlighted to me that the service you receive depends on the disease you have.

In terms of services, which could reasonably have been expected to be involved in respect of John's degree of disability at this time, only Meadow Day Centre was involved. The psychiatrist had given a diagnosis but they had not seen him for approximately a year and a half, there was no social worker involved, no community psychiatric nurse and they had not had any contact

with their General Practitioner. Within the week prior to my first interview with Dillis, a letter had arrived from the General Practitioner asking John to go for an annual review for his, 'mental health problem'. They had previous contact with only two other services, Carers of West Lothian, a representative had visited Dillis at home and provided her with information for carers and a newsletter was regularly sent to their home. The other service was the Day Hospital identified above.

In my second and final interview with Dillis she spoke of the disappointment she felt following their annual review meeting with their General Practitioner mentioned above. This meeting was identified as the annual review of John's mental health problem and the first contact with a doctor for more than a year since his diagnosis.

*We discussed the annual review, when John went to see his General Practitioner, Dillis and her daughter had found this not to be a helpful meeting. She felt there was more about the doctor telling them his problems rather than the other way around. He had asked John one or two questions about his date of birth and things but that was all, there was no further direction as to where to go from there. ....Dillis' understanding is that John missed an appointment with Dr. \*\*\*\*\* (Consultant Psychiatrist) and should have been back to see him after he was diagnosed with dementia, so should have been back to see him some time last year but this appointment had been missed. She wondered perhaps whether this is one of the reasons why they have had such little contact with services.*  
(Second interview with Dillis, 300107)

Fortunately at a consequent meeting with a different General Practitioner there was to be a more productive outcome and the General Practitioner made a referral to a Community Psychiatric Nurse and a Social Worker, they had no further contact with the psychiatrist. Positively these services began to engage, however within two months of my final interview with Dillis, her husband was admitted to a unit to await a place for continuing care. He had begun to walk out of the house and Meadow Day Centre and, unlike previous occasions, had not returned. This developed into a high-risk situation and caused significant distress to Dillis as he was found walking along busy roads and would go missing for hours and the frequency of this behaviour was escalating. This finding is consistent with Bell et al (2001) who identified a direct correlation



between increasing burden on the family carer and admission of the PWAD to a care home.

My analysis of this situation was that care and support for both John and his wife had been compromised due to the lack of a designated person overseeing their changing situation. It was evident that initial support following a diagnosis of dementia, in the form of the day hospital, had been organised by the consultant psychiatrist. When this intervention had failed, no other mechanism was put in place to oversee and assess the changing situation. Coupled with a missed annual appointment with the psychiatrist, this resulted in an unmonitored and unsupported situation.

It is evident from the interview data included within this chapter, that Dillis and her daughter had the responsibility of flagging up their problems as carers to local services. They could be described as being passive in that they did not challenge or push service providers to give more help. There are a potential number of reasons for this, which will now be discussed. They did not understand the system of health and social care and who to approach for help and indeed what help was available. They assumed that the engagement and information from service providers, which they had experienced, was the norm. They had no baseline expectations or experiences to act as a comparator. Dillis implied during her interviews that if no help was offered, then it was either not available or not appropriate for them at this point in time, she had a sense of trust in medical staff. It is notable through the interview excerpts however; that this trust and respect diminished when the annual review with the General practitioner was deemed unhelpful and a sense of dissatisfaction prevailed.

Dillis' energies were focused on continuous caring and muddling through; she had little physical or psychological energy to focus on pushing people to provide additional help. There was also a sense that whilst within the caring role she tried to just cope and tackle the next problem to arise. She did not have a 'bigger picture', of unmet need; she was lost in the provision of continuous caring and adapting to change. The sense from Dillis was that it

was her responsibility to care. This picture is consistent with Buijssen (2005) who identified that Carers can place impossible demands upon themselves, namely that the PWAD must be happy and all their physical needs met, this is not possible and failure is inevitable.

Within the above context it is almost impossible to determine how Dillis could manage increased financial responsibility and management, as identified by the Scottish Executive (2005). One of their developments to support family carers is to offer cash payments rather than services so that unpaid carers can arrange care according to needs and preferences. In principle this would appear a useful intervention. In Dillis' situation this would mean an additional layer of activity and would require an awareness and knowledge of available services. It would also involve employing services providers and managing finances and other related care processes, for example meeting the health and safety requirements of paid carers in their home. In order to be a successful support strategy, Dillis would have required intensive support from a professional to guide her through this overall process.

The multiple factors described above regarding acceptance and satisfaction with carer support interventions, was further compounded by a lack of continuity when services did engage in providing support. A General practitioner referred John and Dillis to a community psychiatric nurse for the elderly and a social worker. The social worker saw the family once, the CPNE saw them three times but on the third occasion transferred their care to another day centre and the Charge Nurse from this service became the key worker. John never attended this day centre as his walking out of the house and the day centre became too problematic. The social worker stated that the referral was made too late and the issue became one of a need for transfer to a continuing care setting.

Reviewing the whole situation, it could be argued that John and his wife were lost in an uncoordinated support system. That help came too late and when services did engage the approach was disjointed. The Consultant Psychiatrist

and General Practitioner failed to monitor, understand and act on the deteriorating situation, crucially failing to engage available services that could have provided additional carer support.

This perspective however is derived from my own professional comparisons and experiences of cancer services. These services have greater funding, greater degree of availability and work in a more co-ordinated fashion, particularly between generic and specialist services. Dillis' perspective and experience however is one of a significant life changing struggle and an awareness that she didn't get much help other than from Meadow Day Centre, a service she in fact sought out herself.

Within the needs assessment conducted as part of this research (Chapter three), it is evident that John and Dillis' situation was not unusual. One of the needs identified for PWAD and their carers was for a 'live', professional contact. Someone who would have an identified ongoing involvement, who would get to know the PWAD and their carer over time and act as a point of contact. They would flag up changes and needs to relevant professionals and services. This professional would understand systems of health and social care and have authority to refer and engage services. This approach would be proactive, supportive and co-ordinated, and would aim to address the multiple difficulties experienced by John and Dillis described above. This model of care exists in other settings and for other disease processes, for example breast cancer and heart failure. Heart failure nurses based in West Lothian work with clients on a continuing basis and see them in both the primary care and hospital setting. Such an approach could also be described as consistent with notions of personhood and understanding the person behind the dementia (Kitwood, 1997). It would also be in alignment with Nolan et al (2002) principles of understanding the complexities of caring situations and giving consideration to what the carer would consider to be successful interventions. This represents a highly individualised approach and reliant upon measuring outcomes against in-depth and accurate assessment of the carers' needs.

#### **7.4.3 Services for PWAD and carers were disconnected resulting in blocks to information sharing and access to services**

A further example of services for PWAD being disconnected arose during the research at Meadow Day Centre. During regular reflection and action meetings with staff, it became apparent that Jean in her role as manager of the day centre had attempted to highlight the situation of John and Dillis. She expressed her concern about the lack of support they were receiving at a monthly dementia liaison meeting. The following extract of data is taken from a reflection and action meeting held on 050207.

*We also talked about how John seemed to have fallen through the net in terms of support and how this seemed to be related to not getting an appointment with the consultant psychiatrist and that seemed to be missed and that he did not get access to services for a long time. We discussed the \*\*\*\*\* dementia liaison meeting, Jean discussed the fact that she had talked about John twice at this meeting, raising up concerns about how he was and how he was coping also how his wife was coping. However he was not on anyone's caseload, neither social work or CPNE, so therefore nothing happened with this information, it did not go anywhere and no action was taken. We discussed that this was a key area for voluntary services being able to fully participate in meetings and be able to highlight the needs of people involved with them but also to be able to access other services as appropriate. There would seem an issue here about services working together and valuing the work done by both voluntary services and NHS and council services. In this aspect it would seem that the liaison meeting failed to meet it's objectives but perhaps the objectives were only for the CPNE and Social work staff to discuss their patients and there is not the opportunity to bring on anyone new.*

(Notes from reflection and action meeting, p1, 050207)

This data provides further evidence that John and Dillis were not on the caseloads of key professionals working within the local area. When Jean, as manager of the day centre, flagged up their situation, no action was taken. The data points to the potential cause of this being that Jean represented a voluntary sector service and as such had less status and ability to influence outcomes. On further analysis this is too simplistic. On a number of occasions during our reflection and action meetings, we had debated whether the staff from Meadow Day Centre could refer directly to CPNE's or Social Workers. They were comfortable to make contact if they knew one of their clients was

already identified as being on a caseload of one of these professionals but they were uncertain about making a direct referral.

There were occasions when the day care staff did not know if the client had a social worker or CPNE involved with them, particularly if a referral to one of these services took place after the admission to the day centre. Historically they had pursued a process of getting the client or carer to make an appointment with their General Practitioner to discuss health problems or the potential of a referral to another service. Jean and Tam were aware however, that this approach put the onus back on the family, which was not wrong but in some situations a more direct approach may be more appropriate. This data highlights a lack of liaison between these services, despite a system being in place where information could be exchanged and acted upon. For Jean and the day care staff this was demoralising, they were aware of the problems but seemed powerless to get health and social care services to act. The data highlights a need for clarification of the purpose of the liaison meeting, who can attend and the responsibilities of participants.

A further example of disconnected local services for PWAD occurred during an action learning set. The set was held in Meadow Day Centre and there were photographs of their clients displayed on the wall. The key representative from the community hospital, who was attending the action learning set, identified the photograph of one of their new clients who had just commenced a respite admission within her ward. The nurse had no idea that this client attended Meadow Day Centre, there had been no record of this in her admission information. The day care staff acknowledged that they had experienced this before. Within the health records of clients there was no mention of attendance at a social services day centre. It became clear in the discussion that followed, the day centre staff had valuable information about the client from their experiences of working with them and the relationships they had. The community hospital staff were struggling to help this patient settle into the ward. The day centre staff knew this particular client had been admitted for respite, but did not know which facility.

This situation provides further evidence that opportunities for services to work together and share information, which could be directly beneficial to the client and the family carer, were lost. This represents additional barriers to pursuing a relationship centred approach to care for someone who has severe difficulty with verbal communication. Where relationships and effective ways of caring were established, the disconnection of services stifled valuable exchange of information.

The evidence of disconnected services presented above, is consistent with the research conducted by NHS Health Scotland (2003). They recommended a need for interventions that reduce isolation for carers. Recommendations included additional help and co-ordination from General Practitioners, additional support from home help and additional respite support and sitter services.

### **7.5 Meadow Day Centre's influence on local health and social care dementia services**

In this section an action spiral will be presented describing how Meadow Day Centre attempted to initiate change by influencing local health and social care services to adopt a more joined up approach for PWAD and their carers.

As described above in section 7.1 Jean and Tam requested help from the wider dementia care community to support them in their aim to enhance the dementia care provided at Meadow Day Centre. They brought together a group of dementia care providers to support them to develop their practice. This group included representatives from Alzheimers Scotland and the Dementia Services Development Centre at Stirling University including local care providers such as Community Psychiatric Nurses for the Elderly. In the usual manner of staff at Meadow Day Centre, this plan was acted on quickly without too much consideration of what they were asking for or how this support would work or how the variety of organisations involved would sustain their support. There

was no additional funding for this development. These activities occurred early in the involvement of Meadow Day Centre in the research.

The first two meetings were very well attended but what took place was not what had been planned. Discussions focused on the disjointed nature of wider dementia care in West Lothian and the need to develop a strategy and a dementia care pathway. The greater need focused on the wider situation not what had been intended, dementia care at Meadow Day Centre. One reason for this was potentially a lack of clarity regarding the original aims of what they wanted to achieve at the first meeting but also those who participated brought a wider agenda and this forum provided an opportunity to take more strategic issues forward. It was agreed at the second meeting of this group that the membership of the group would be reviewed and its function would be twofold: to develop a West Lothian Dementia Strategy and also undertake uncompleted work, namely develop a Clinical Pathway for Dementia. Dementia clinical pathway work had been commenced two years previously in West Lothian but had ceased to function for a variety of reasons and the development not completed.

It was evident that there were many professionals who saw this as a priority as subsequent meetings were well attended. Managers, senior clinicians and a range of representatives from disciplines and agencies engaged in this development. There was much enthusiasm and energy to undertake this work. The Scottish Executive and Alzheimers Scotland Action on Dementia had produced a template for dementia services in 2004, which was a timely and useful document that the group adopted. The Dementia Palliative Care needs assessment, completed as the first part of this research, was also used as a key document as it provided local evidence of need. It was evident that crucial factors were in place, which acted as drivers for this work. A need was evident, documented and recognised, a template was in place which meant that participants could see a way forward and key local people had caught a vision that would achieve something better for PWAD and their carers.

Over a period of eight months the groups however lost focus and attendance at meetings dwindled. There were a number of factors associated with this. The structure of local health care organisations had changed. A new West Lothian Community Health and Care Partnership had been formed and managers were concerned how the dementia work would fit with new structures, targets and ways of working. A concern also arose that no organisation owned this work or had commissioned it, in reality it had emerged opportunistically from an idea of Meadow Day Centre staff. Participants were concerned about putting a lot of effort into a process that may not ultimately be recognised.

*Jean spoke of her own particular goals within this process and that they were to bring everyone together in a way to facilitate things happening and to write the minutes, so take the role of co-ordinator and facilitator. Jean went on to speak about a lull now being in place with regard to the activity of the group (Dementia Steering Group) and that at the moment there doesn't seem to be a direction or focus for the work.....The main issue is about asking the Community Health and Care Partnership for direction, so people working on the strategy would know that it would be something that would be used.....so it needs acknowledgement within the CHCP structures.....Jean spoke in particular about a solution to some of the problems, for example a dementia specialist nurse, who could be contactable throughout the course of the person's illness and would be able to provide input and support on a continuing basis rather than on an adhoc basis, which is the case currently.....Jean described the case of a client at Meadow Day Centre at the moment and the situation with their carer and wondered about writing a case study to try and present and influence understanding regarding the issues about dementia.*

(Notes from action learning meeting, 220906)

This data highlights the lack of progress with the strategy work but also where Jean saw her role in this work. She viewed herself as a co-ordinator and facilitator but her motivation arose from witnessing the reality of care giving from the carer's perspective. This motivation was important, as it was the driver for her activities to promote the completion of the dementia strategy work. During the remainder of the action learning session on 220906, Jean considered practical ways of influencing people from the CHCP.

As a direct result of the collaboration with Meadow Day Centre in this particular action spiral, the dementia palliative care project steering group in conjunction with the five services taking part in the project, agreed to write a letter to key individuals within the new CHCP. The letter would highlight the dementia



strategy work and request clarification of the way forward. The strategic thinking and planning involved in challenging the CHCP arose from Jean's discussions at action learning and thinking strategically how to engage the CHCP management in this process.

*The focus of the presentation generally went on to Jean's role and her expectations and outcomes. TH (Action Learning Facilitator) used a model on the flip chart looking at sphere of influence, for example: what are the specific problems Jean wants to address and how can she influence them. This was a challenge left for Jean to consider as to what things she could actually do something about and how could she do that by taking best advantage of situations and discussions that take place.*

(Notes from action learning meeting, 220906)

An interesting aspect of action learning is that all participants are actively engaged in learning not just the presenter, in this case Jean. Throughout Jean's presentation I was conscious of my own role in the strategy work and how I could influence and develop this work within the new CHCP structure. The questions although aimed at Jean were relevant to each of us and had an impact on our thinking and planning.

Events that followed were the drafting and agreement of a letter by members of the dementia palliative care project steering group, the five participating services and the chair of the recently formed dementia strategy group. The letter was sent to key individuals in the CHCP, the Director, the Head of Health and the Chair of the Older People and Physical Disability Management group. Two months passed with no response to the letter then I was asked, along with the chair of the West Lothian Dementia Palliative Care Project Steering group to attend a meeting of the CHCP, Older People and Physical Disability Management group. I gave a presentation at the meeting, which was followed by a period of discussion. The outcome was that the group would consider the ongoing development of the strategy but not in isolation, broader strategic work needed to be undertaken which involved the full remit of this group's responsibilities. This involved broader issues such as mental health for older people, not only dementia and also the development of a disability strategy.

My reflections following this meeting included a sense of surprise. I was surprised that an Older People and Physical Disability Management group, for a joint social and health care organisation, had not considered strategic planning work from the onset. I was also pleased that the collaborative work undertaken by the research could influence their thinking and activity. The local evidence was strong and relevant and it was not possible to ignore.

The outcome was that the CHCP Older People and Physical Disability Management group identified the need for the development of a strategy. The strategy they planned would have seven strands, one of which was mental health and dementia. The dementia strategy group was reconvened and the work progressed. This work is a lengthy process and has continued after the life of the research. At the time writing the mental health and dementia strand of the strategy has been completed and is awaiting verification from CHCP management group. Once this has been agreed the work can commence to actually implement the strategy, a key feature being the need for a continuous known contact, a 'live' professional contact who can guide and support but also refer to services for additional support when necessary.

The analysis of this action spiral from the research at Meadow Day Centre is important. The issues of carer support rose from data collected from interviews with families and through the conduct of the case study. This had a motivating impact on Jean, she saw and understood the hard realities of being a carer, but importantly could identify changes that could improve this. She enabled Meadow Day Centre staff to make changes to their practices of carer support but focused her own efforts on a bigger West Lothian picture. Her role of co-ordinating and facilitating brought critical people together to shape change, she knew key players in this situation as she had worked in West Lothian for many years. It could be argued that her initial motives were inward looking, to improve the day care service. She did however recognise a bigger need and was aware of past failed attempts to enhance dementia care (Dementia Care Pathway). Through this she was flexible enough to use Meadow Day Centre as a conduit for a bigger change and adapt her own role within this.

It could be argued that action learning played a vital role in allowing space to consider the actual problems, how to act and what to do. Jean presented this issue on several occasions and it became a collective concern as all five services recognised the disjointed nature of dementia services in West Lothian and the impact of this on carers. Jean could not have achieved this alone, the collaboration with the project steering group, in particular, enabled access to senior managers and clinicians. As an action researcher my own involvement within this situation was important but my engagement was shaped from the data collected and experiences of working with the participating services. I was also strongly influenced by discussions that took place during action learning. Listening to Jean's presentations impacted on my thinking and actions. As Jean considered ways she could influence those she had contact with, I did the same and through different means a collective change occurred. This would endorse the views of McGill and Beaty (2001), 'Individuals learn with and from each other by working on real problems and reflecting on their own experiences...The process helps to take an active stance towards life' (p11).

It could be argued that the fluid nature of the action research process that occurred at Meadow Day Centre was positive at different levels. Within the organisation they implemented and evaluated a number of carer support interventions, which were responsive to need and their local context, rather than fixed to original aims. External to the organisation they were able to significantly engage in a process of change and planning by following local opportunities. Adhering to a fixed process of practice development would have missed key issues related to context, identified need and importantly responding to their own learning through the processes of action research.

It is useful to summarise the key messages from this findings and analysis section about supporting carers of PWAD

The triggers for Meadow Day Centre to change practice were:

- An increased awareness of the experiences of carers and their needs

- Exposure and response to dementia care training and support from the researcher.

The outcomes of changes to practice were:

- A need to provide individual and flexible support to carers rather than group based activities.
- Adopting a formal assessment tool enhanced understanding of carer needs
- A need to continually focus on the views of carers rather than develop practices based on staff perspectives.

Factors that restrict access to support for family carers were:

- The ongoing provision of care for the PWAD took precedence over carer needs and wishes to engage in support activities.
- The physical and psychological affects of caring, negatively impacted on the motivation and ability of carers to participate in support activities.
- The principle of group-based support was welcomed but did not prove a practical option for the small group of carers connected to Meadow Day Centre. Individual and flexible support options were preferred and proved viable.
- The behaviour and preferences of the PWAD became key factors in the services available to carers, consequently having further impact in terms of access to support.

Factors that result in the needs of carers being hidden to service providers were:

- Services for PWAD in West Lothian were disconnected resulting in ineffective information sharing and referral processes.
- There was no evidence of ongoing, 'live' access to professionals to guide and support carers.

- The data gathered during the case study, identified that the PWAD had an effective social façade which acted as a further barrier to service providers understanding and responding to the family carer's needs.

Meadow Day Centre was able to influence local strategic health and social care dementia services because:

- They developed an in-depth understanding of the needs of carers and wanted to make positive changes.
- They felt they were on the periphery of services and saw gaps in joint working, identifying a need to proactively make connections between services to enhance carer support
- A local restructure of health and social care services provided an opportunity and driver for change
- The research enabled structured and shared reflection processes which facilitated a considered and strategic process of influence
- The day centre was able to join with other participants from the project and members of the steering group to jointly influence this process
- The needs assessment conducted as part of this research and a timely dementia care template from the Scottish Executive provided local evidence and framework to proceed with this work.

This chapter has identified the triggers that stimulated changes to practices in supporting carers at Meadow Day Centre and how staff learnt about providing flexible and individual support interventions. Specific barriers were identified that block carers accessing the support they would like and the chapter concluded by analysing how the day centre was able to influence strategic plans within the local area. It is necessary to consider specific recommendations from these findings, these are included in chapter nine.

## **8. Research conclusions and discussion**

In this chapter the research aims will be reviewed and discussed in light of the findings and analysis detailed in chapters six and seven taking into consideration the literature and research evidence reviewed.

### **Research aims**

1. Identify the palliative care needs of people with dementia and their carers in West Lothian.
2. Describe and analyse two dementia care services in West Lothian as they develop an aspect of their palliative dementia care practice: specifically the assessment and management of pain and distress for PWAD (Almond Ward) and supporting carers of PWAD (Meadow Day Centre).
3. Analyse the learning that occurs between dementia care practitioners and a facilitator experienced in palliative care during this action research.
4. In relation to the assessment and management of pain and distress for PWAD and supporting carers of PWAD, determine potential future implications for practice development and service delivery.

### **8.1 Research aim one: Identify the palliative care needs of people with dementia and their carers in West Lothian.**

As described in chapter four, six key priorities were identified from the dementia palliative care needs assessment conducted in West Lothian. These were:

1. Provision of person centred care
2. Management of pain and other symptoms
3. Carer support
4. Provision of respite care
5. Equity of access
6. Development of a strategic group with responsibilities for dementia care in West Lothian

These needs were consistent with other research conducted with PWAD and carers. The need for a strategic dementia group however was a local issue arising from the absence of strategic direction for dementia care, in particular, as a result of dementia care being subsumed under the broader umbrella of older people's services.

#### **8.1.1 Implementing person centred care and symptom management**

Bender (2003) highlighted that a need existed for the development of practical ways of providing person centred care, developing on from the moral and ethical framework initiated by Kitwood in 1997.

A tension exists however in regard to the focus on person centred care for the PWAD. Further evidence from this needs assessment highlights the significance of family within this equation. Supporting carers as an integral part of care for PWAD, was highlighted as a specific need in this assessment. Person centred care does not acknowledge the role and significance family carers can play in the care required by the PWAD, in both acknowledging and practically implementing care that is focused on the personhood of the PWAD (Bartlett, 2000). The literature review presented in this thesis focused on the 'skewed' nature of person centred care (Nolan et al, 2003), it does not recognise the relational aspects of being a person and how this reflects within care. Dewing (2004) highlighted that terms such as person centred care have an appeal, as they appear to make sense and appeal to the aims and values of practitioners, however they remain difficult to practice in reality (Killick and Allen, 2001). Considering the necessary shift in focus identified by Kitwood in 1997, from the medical model of care for PWAD to a process that focuses on the person, research and evidence from this research would indicate that a further shift is required to focus on relationships. This is not to minimise the personhood of the PWAD, but rather enhance this by understanding relationships and utilising this to ensure care for the PWAD is based on them as a person within the context of their relationships (Tresolini and Pew-Fetzer Task Force, 1994). This approach would also be consistent with a palliative

care approach that attempts to view the person as a whole. 'A palliative care approach involves a focus on: quality of life, good symptom control, a whole person approach, care for the person and those that matter to them, respect for autonomy and choice and an emphasis on open and sensitive communication,' (Scottish Partnership for Palliative Care, p10, 2006). This definition provides a more balanced approach and acknowledges the broad nature of relationship centred care. It can be argued that in the context of what has been discussed, following a palliative care approach for PWAD is an appropriate model when delivered in the context of relationship centred care. As the PWAD moves to a severe level of their disease, the necessity of including and acknowledging family carers to ensure personhood is maintained, but also to provide carer support can be seen as an appropriate palliative care model for PWAD. This is particularly evident when consideration is given to a potential prognosis of 10 years and the potential severe loss of abilities to communicate verbally during the severe phase of the illness.

An inconsistency exists however between adopting a palliative care approach within the context of relationship centred care. Tresolini and the Pew-Fetzer Task Force (1994) in their definition of relationship centred care highlight the importance of relationships between service providers and patients / clients as well as relationships between families. The acknowledgement of service providers within this context is not highlighted as part of a palliative care approach. Within a palliative dementia care perspective the importance of including service providers within this model could be argued as necessary. Data from this research has identified that service providers can become the PWAD's substitute family, as actual family members struggle with the ongoing demands of being a carer and withdraw from the situation. Also the relationships between service providers and PWAD can provide the basis for providing effective symptom control, promoting autonomy and respect, and ensuring appropriate support is provided to the family. This research would suggest that service providers, as a group, should be specifically acknowledged within a palliative dementia care approach. Specifically in relation to the relationships they have with PWAD and family carers and that this forms the



platform for multiple palliative dementia care interventions, such as providing effective symptom control.

Managing pain and other symptoms for PWAD, such as confusion and distress (Regnard 2006, Cunningham 2006, Morrison et al 2000, Weiner 1999) has a growing research base identifying that this is a service development need. As stated above a relationship centred approach between family carers and PWAD could assist with the provision of effective symptom management. As identified within the literature review, organisations representing PWAD and family carers such as Alzheimer's Scotland and the Alzheimers Society have identified a need for enhanced symptom control and particularly avoidance of unnecessary clinical procedures such as the insertion of feeding tubes (Alzheimers Society, 2004).

### **8.1.2 Carer support**

When considering carer support for PWAD there again is a growing body of evidence that highlights the needs and significant challenges experienced by this group (Bell et al 2001, Torti et al 2004, Buijssen 2005) and also what support strategies appear to help (Brodaty et al, 2003). Concern around the absence of an individual way of evaluating carer support has been acknowledged (Nolan et al, 2002).

In regard to the data gathered for this research, specifically hearing the voices of family and their experiences of caring, it is evident that within a dementia context, family carers are essential and critical to any approach to caring. From this research, issues such as advocacy, maintaining personhood, autonomy and independence are all activities family carers have engaged in, within the context of their unique relationship with the PWAD.

### **8.1.3 Respite care and equity of access to services – Key issues**

The provision of respite care and equity of access to services are related and have both a local and broader evidence of need. Scottish Executive (2005) identified that giving unpaid carers a right to regular breaks from caring and providing more and better quality respite options would most address the needs

of carers. It was important to understand this in terms of the local context of West Lothian. Within this research, factors such as the age of the PWAD were crucial in determining the availability and accessibility of services. For people with early onset dementia they received very positive age specific, specialist support but were disadvantaged in terms of in-patient respite (usually a care home) as their age related needs were different to others receiving the service. Data from older people who have a dementia and their carers in this research, identified a lack of options for respite care both in regard to support within the home of the PWAD and from services such as day care. Data collected subsequent to this needs assessment, also identified a lack of co-ordination of care and services, indicating the possibility of sub optimal utilisation of available respite services. This situation would further negatively hamper the experience of respite care for PWAD and their carers.

It is worthy to note that out of the six key priorities identified from this palliative care needs assessment, three specifically relate to the experience of carers: carer support, respite care and equity of access to services (including respite services). It could be argued that a model of palliative care for dementia care would require involvement and support for carers as a key and vital element. Also, the emphasis on carers could have a higher priority than models of palliative care for other diseases, where the person's mental state is less severely affected. The length of prognosis, the change in relationship over time, the altered communication, potential to cope with challenging behaviour, the certain and increasing dependency both physically and mentally, the impact on social and financial circumstances are key issues that justify a focus and priority on carers (Bell 2001, Torti et al 2004, Markowitz et al 2003, Maas et al 2004). All palliative care situations are unique and will have a significant impact on the family and carers of those involved. Not all however will necessitate such a sweeping impact on the life of a carer over a prolonged period of time.

**8.2 Research aim two: Describe and analyse two dementia care services in West Lothian as they develop their palliative dementia care practice: specifically the assessment and management of pain and distress for**

## **PWAD (Almond Ward) and supporting carers of PWAD (Meadow Day Centre)**

In Chapter five there is a description of the two services that participated in the research. This description was based on data collected to develop a baseline understanding of each service. On completion of this data collection a further process was undertaken to specifically identify the views of service providers in regard to their area of dementia palliative care practice development. This data collection identified beliefs and values of staff in respect of the assessment and management of pain and distress for PWAD (Almond Ward) and supporting carers of PWAD (Meadow Day Centre).

In this chapter sections 8.2 and 8.3 will outline the research conclusions from research aim two. Section 8.2 will outline the conclusions from Almond Ward regarding the assessment and management of pain and distress for PWAD. Section 8.3 focuses on the conclusions from research conducted at Meadow day Centre, specifically supporting carers of PWAD.

### **8.2 The assessment and management of pain and distress for PWAD (Almond Ward)**

#### **8.2.1 The complexity of assessing distress**

Through data gathered from case studies in Almond Ward, including participant observation, interviews with family and reflection and action meetings with staff, this research identified how complex it was to interpret and understand the distressed behaviour of a person with advanced dementia, who also has severe communication difficulties. Within an in-patient community hospital setting, this complexity was evident for both staff and family who both knew the PWAD well. The researcher hoped that the 'in depth review' of these cases, involving and hearing the voices of the patient, their family carers and staff who knew the patient, would provide answers. Despite the collective voices and collaborative nature of this approach, this evidence highlighted a very challenging situation for a team of nurses on this ward as they attempted to observe for signs of

distress, understand the cause of the problem and take effective action. These findings are congruent and consistent with current literature. For example, Regnard et al (2006) work where the complexity of assessment was identified for people with a learning disability who have difficulty with verbal communication.

The nature of this complexity makes it difficult to understand the benefits of utilising brief and seemingly superficial assessment tools such as the Abbey pain assessment tool for PWAD (Abbey, 2002), however it could possibly be argued that a consistent process however superficial, is better than random recording of a range of observations by different nurses who have varied experiences and knowledge.

The complexity of assessing non-verbal older adults has been highlighted repeatedly in the literature. This is evident, for example, in the variety and number of pain assessment tools available for this particular group and the ongoing research attempting to determine their appropriateness and utility (Herr et al 2004, Hurley et al 2002, Snow et al 2004). The findings that follow in this chapter will outline approaches that were evident in practice that aim to tackle this complexity.

### **8.2.2 The appropriateness of the DisDAT for PWAD**

This research utilised an assessment tool called the DisDAT, originally designed for people with a learning disability, it proved to be an appropriate tool for use with PWAD who have limited verbal communication. The tool provided a person centred framework for assessment, particularly within a continuing care setting. The tool was person centred in that it focuses on the individual's behaviour within their context. The assessment does not involve comparison with other people or generalised measurement scales. Distress and contentment are characterised by the individual's behaviour over time and assessed by those who know the person. In order to achieve this degree of person centredness, the tool could be described as complex. Completion of the tool requires careful assessment and professional judgement as well as

consensus amongst staff. In terms of the Person Centred Nursing Framework (McCormack and McCance, 2006) completion of the DisDAT would be classified as a person centred process. However, it could be argued that staff used a relationship centred approach (Tresolini and the Pew Fitzer Task Force, 1994) to use this tool in practice. Staff completed the DisDAT whilst working alongside the patient over time and when working with one another. They used their relationship with the patient to determine their behaviour, what behaviours were expected and unexpected, and what behaviours they suspected may indicate distress. They also used their relationship with one another to compare and debate what they saw and identify meaning. Patients within the context of Almond Ward, react differently with individual nurses dependent upon a number of factors, which includes their relationships. Regnard et al (2006) in their paper identified the importance of ensuring that people who know the person well complete the behavioural assessment and this approach ensures consistency of information.

These findings echo the work of Regnard et al (2006) with people with a learning disability and determine the feasible and appropriate transfer of this tool for PWAD. In summary, it could be argued that the tool provides a practical application of person centred care approaches (McCormack and McCance 2006, Kitwood, 1997), but it also utilises relationship centred care, (Tresolini and the Pew Fitzer Task Force, 1994) in terms of its application to practice.

### **8.2.3 Necessity of clarifying what is meant by the term 'distress'**

A challenge identified in the research was the term, 'distress', required debate and clarification amongst nursing staff as it was evident differing views and values were held as to what distress looked like. Potentially this is an issue specific to a group of nurses working within an in-patient setting, this issue was not identified by Regnard et al, (2006) in their research. It is entirely perceivable that the local context, culture of working and practices of nurses would come into play here and impact upon the understanding of this term. It is noteworthy that the nurses from Almond Ward involved in this research, identified distress as a degree or level of behaviour that was severe in nature and this definition

was identified in respect of comparisons between patients and their past experience. The term distress required deconstruction in order for nursing staff to consider this from the perspective of individual patients. The author of this paper was surprised by this finding as individualised care practices and problem solving, based on knowing the person, were often debated amongst staff and acknowledged as good dementia care practice. In relation to understanding and working with the term distress, this person centred focus had been lost and required consideration and review. In some respect this was all the more surprising as one of the reasons for selecting to use the DisDAT was its provision of a baseline understanding of the person that could be useful in a variety of ways.

This finding emphasises, that even in a ward focused on individualised care, where this is discussed, and actively promoted, there is a need to consistently review practices in relation to what McCormack and McCance (2006) identify as person centred processes. Language, culture and experiences can strongly impact upon ideals and the outworking of nursing theory.

#### **8.2.4 The benefits of group rather than individual assessment**

An important aspect of completing the DisDAT was the requirement of a group of nurses to debate and then agree assessment findings. Nurses were uncomfortable completing this independently and a group assessment provided confidence in the process. This is consistent and reinforces Regnard's et al (2006) findings. With any assessment tool that relies on the observation of behaviours without the verification of the patient, a group decision-making process is valuable. This finding was reinforced from other data from the parent research project where a specific pain assessment tool was implemented, the Doloplus 11 (Wary et al, 2001). Staff in this situation, also identified a degree of confidence in the assessment process when completing the Doloplus 11 as a group.

It could be argued, that the group decision-making process adopted for the DisDAT represented a relationship centred process (Tresolini and the Pew Fitzer Task Force, 1994). As discussed above, nurses completed the DisDAT

whilst working with the patient. This involved observing their behaviour within the context of their relationship and prior knowledge of the person. The group process allowed staff, who have different relationships with the same patient, to compare and debate the behaviours observed and identify meaning. This process also acknowledges the relationship between nurses as a group. Group decision making, in the context of the assessment of distress and pain for PWAD within in-patient settings, has received minimal attention in the literature to date. In terms of assessing behaviours of non verbal PWAD, group assessment processes would appear important in order to justify the meanings attributed to behaviours and for this to involve a consensus approach. In terms of implementing this assessment process in practice, group decision making increased confidence in the process.

#### **8.2.5 The benefits of considering distress before focusing on pain**

Within the clinical context of this research setting, the nursing staff identified it was beneficial to consider a broader notion of distress rather than initially focus directly on the subject of pain. This approach was appropriate to the patient group but also for the staff, they needed a system to aid their decision making about a small but consistent number of patients who appeared distressed. This approach is also consistent with findings identified above regarding the complexity of assessing this client group. There is potentially a risk of missing a cause of distress when there is a sole focus on the issue of pain in the first instance. Taking a broader approach enabled a rounder view, particularly appropriate when there could be potentially multiple factors causing a problem for the PWAD.

#### **8.2.6 Nurses expectations following implementation of the DisDAT**

The implementation of the DisDAT, raised initial expectations amongst nurses that distress and pain would be easier to manage, this was not the case as clinical judgement was still required and clinical decisions remained challenging despite the completion of a robust and systematic assessment process. There was a sense that implementing a research based assessment tool, would provide the answers necessary to make this process easier. In a real sense the

nursing staff were aware of the difficult debates and different opinions they had about the complexity of assessing behaviours, however they had focused for a long time, prior to this research on implementing an assessment tool. In some sense the tool could have been perceived as a 'magic bullet'. A significant amount of literature and evidence points to the practical challenges and complexities of implementing such assessment processes (Frampton 2003, Ferrell et al 1995, Cohen-Mansfield 2002b, Scherder et al 2005a, Cunningham 2006). It is understandable, perhaps, that nursing staff would however consider the process of implementing the DisDAT as a solution and cure for this problem, as opposed to a complex process tackling a challenging clinical issue.

### **8.3 Research aim two: Describe and analyse a dementia care service in West Lothian as they develop their palliative dementia care practice: specifically supporting carers of PWAD (Meadow Day Centre)**

#### **8.3.1 The benefits of formal carer assessment and a need for individual, flexible carer support interventions**

Adopting a formal assessment tool, The Carers Checklist, (Mental Health Foundation, 1998) enhanced the day care staffs' understanding of the needs and perceptions of the carers they had contact with. In response to this, staff were able to plan and support carers according to their individual preferences and situation. The experiences of staff were that carers accessed the support offered to them, as they were able. There were some family carers who did not engage with offers of support. As previously identified, the numbers of carers of PWAD involved with the Day Centre were small. At the time of conducting this research, NHS Lothian had implemented a formal policy to conduct Carer's assessments. This assessment was required to be completed by any healthcare or social care professional at the request of the carer. Evidence from the steering group and professionals involved in the research, identified that only a few carer assessments had been completed, the reasons provided for this were the comprehensive nature of the assessment, and completion of the assessment resulted in little benefit to the carer. This later outcome related to the restrictions associated with available services, staff could not provide



additional services / support interventions that were not available locally. The comprehensive nature of the assessment meant that it took more than an hour to complete. This was a barrier for both practitioners and carers. In relation to Meadow Day Centre's experiences of implementing an assessment process, their autonomy meant that they could offer a range of options to support carers as a direct response to the assessment, a support group, drop in support service, information and a range of interventions for the PWAD. The experience of implementing a local carers assessment did not share the same outcomes as the broader NHS experience.

Through the action phase of the project it became increasingly evident that when developing carer support services there was a need to continually focus on the views of carers rather than develop practices based on staff perspectives of need. This is consistent with literature that emphasises a need for partnership and collaboration within the clinical context, specifically partnership between PWAD, their carers and service providers (NHS Health Scotland 2003, Scottish Executive 2005). This is also in keeping with the notion that interventions should be tailored and appropriate to the individual needs of carers (Scottish Executive 2005, NHS Health Scotland 2003, Nolan et al 2002)

Evidence from the carers of PWAD that attended the day centre, identified that their preference for support interventions, were those that were individual and flexible. For example group support sessions were felt to be useful, but difficult to attend due to care commitments for the PWAD, but regular and planned follow up phone calls from staff to carers, in particular, were identified as practically feasible and useful. The Scottish Executive (2005) in their large-scale research about understanding and improving the situation of unpaid carers, identified a need to shift control and choice to carers. This is indeed a laudable aim and few would argue with this principle, however carers in this study, identified that their caring commitments took precedence over their personal wishes or needs to access support and training. The PWAD needs took priority over those of the carer. The practical requirement needed to support this change would involve flexible care options for the PWAD to allow

the carer opportunities to access these services. Flexible care options for example being, someone to be with the PWAD at home, or providing supervision / care for the PWAD at the same time and venue as the carer support activity. It could be argued that this scenario represents a vicious circle. Unless more flexible and an increased number of direct care options for PWAD are provided, carers will struggle to access the forms of support they themselves have identified as useful to the government. In respect of the Scottish Executives (2005) research, it is fair to state that they also acknowledged this need and identified that unpaid carers should have a right to regular breaks from caring and the provision of more and better quality respite opportunities.

### **8.3.2 Factors that restricted family carers access to support**

There is a growing evidence base that identifies the demanding and stressful nature of being a carer for a PWAD and how this can directly impact on the psychological, physical and social elements of their life (Maas et al, 2004 Brodaty et al, 2003 Markowitz et al, 2003 Torti et al, 2004). This research strongly supported these findings and in addition identified specific reasons why family carers' ability to seek support during their caring experience was restricted. It was identified from family carers associated with the Day Centre, that the ongoing provision of care for the PWAD took precedence over carer needs and wishes to engage in support activities. However interesting or necessary the carer support was felt to be, there was no option other than to ensure the safety and well being of the PWAD in the first instance. Carer's involved in this research struggled to access family and friends to provide 'cover,' at these times. Other factors related to this were the behaviour of the PWAD and the degree to which other family and friends felt able to provide supervision. Also, time away from the PWAD was a precious commodity and it was difficult to stretch the informal respite options already in place.

The physical and psychological affects of caring, negatively impacted on the motivation and ability of carers, to participate in support interventions. Carers described the following as barriers to accessing carer support: physical and

mental fatigue as a result of continuous caring over a period of months / years, and the impact of their own health problems on energy levels and motivation (the majority of carers were elderly).

The behaviour and preferences of the PWAD became key factors in determining the respite and support services available to carers. For example the PWAD rejecting the services of a day centre resulted in the loss of regular respite for the carer and also the loss of information from service providers experienced in dementia care. The lack of options in terms of respite and support services for the PWAD, also had an impact on this situation. Should the PWAD not settle into a routine of attending a day centre and this becomes problematic, there may be no alternative service available. This difficulty also arises within the home situation. From the case study conducted at Meadow Day Centre, the carer expressed a difficulty that her husband, who had a dementia, was unhappy about people coming into their house, he was suspicious of them. The consequence of this was that potential services available to them were further reduced. The carer had to consider the benefits and risks of visits to their home by health and social care professionals. These findings demonstrate how the experiences of PWAD can have a direct and important impact on the support available to carers.

### **8.3.3 Needs of carers hidden to service providers**

When consideration is given to the fact that family carers have a critical role to play in the experiences of PWAD (for example, at diagnosis, providing care and support interventions, and transition to continuing care) this highlights a need for services to acknowledge this important role and appropriately respond to the needs of carers (Davis and Nolan, 2004 Health Education Board for Scotland, 2003). This research identified a series of factors that resulted in the needs of carers being hidden to service providers. Services for PWAD in West Lothian were disconnected resulting in ineffective information sharing and referral processes. This situation meant that carers lacked guidance through their caring experience. The notion of a care pathway, where different services can be utilised according to need was also absent as a result of the disconnection

between local services. Services utilised by carers and PWAD did not share their knowledge therefore important information, that would enable individualised care, and a continuity of approach was lost.

A further complicating factor identified from the data gathered during the case study, highlighted that the PWAD had an effective social façade, which acted as a further barrier to service providers understanding and responding to both his, and the family carer's needs. Even the day centre staff, who had the most contact with the PWAD and where staff knew him, were unaware of the severe level of his disability due to his effective façade and guarded behaviours. On a similar theme, there was no evidence of ongoing, 'live' access to professionals to guide and support carers. It could be argued that this involvement from a professional could enable effective sharing of appropriate information to services when this was required, but also assist the carer to navigate the possibilities of support available from health, social care and the voluntary sector. Ongoing support from a professional could also effectively utilise a relationship centred approach to care for both the PWAD and the carer (Tresolini and the Pew Fitzer Task Force, 1994). The PWAD and the carer would benefit from a professional working with them over time, where a relationship could be developed. The benefits of a relational approach could spill over to other service providers at the point of referral. For example the professional could transfer useful information about the PWAD as a person and how to connect and engage with them, knowledge gained from a working relationship.

Within the case study at Meadow Day Centre, the Psychiatrist and General Practitioner's inability to monitor and initiate appropriate and timely support had an isolating and significantly negative impact on the experience of the carer. Professionals such as these, have a pivotal role in assessment and initiation of support services, therefore when the needs of PWAD and their carers are missed, this can have a deleterious impact on all concerned.

Although there have been positive government and practice development surrounding the needs and activities available to support carers (single shared assessment, carers assessments, cash payments to carers), the uptake of these initiatives appears to be slow and their impact on supporting carers presently uncertain (Scottish Executive 2005, NHS Scotland 2003, Carradice et al 2003). Further research is required to investigate the specific perspective of carers regarding the practicalities of receiving individual supportive interventions such as these. In the light of the case study discussed above, the carer would have struggled to manage an initiative such as the organisation of cash payments for carers. Caring fatigue, low motivation and the confidence to undertake this activity would have arguably acted as barriers.

It is evident from the findings of this research that multiple factors, related to the organisation and provision of services to individual factors, resulted in the needs of the carer being hidden.

#### **8.4 Research aim three: Analyse the learning that occurs between dementia care practitioners and a facilitator experienced in palliative care during this action research.**

As the facilitator of this research, I learnt a substantial amount of new knowledge and developed new practice skills in dementia care whilst conducting the needs assessment and whilst gathering baseline data from participating services. During the needs assessment it is necessary to highlight that much learning transferred from dementia care practitioners to myself and built upon my existing knowledge about principles of palliative care but on this occasion focused on those with a dementia and their carers. This new learning focused on the following: understanding dementia related disease processes, approaches to managing behaviour, identifying personhood and providing care in an individualised way, the impact of the environment, making connections with the PWAD and understanding the perceptions of family carers. In retrospect a phenomenal degree of learning and new understanding as well as development of skills in practice.

#### **8.4.1 Researcher developed new understandings of person centred and relationship centred care**

Working with PWAD, their carers and service providers, and reading literature about dementia care, changed my understanding of person centred and relationship centred care. The need to understand, accept and develop relationships with PWAD, when they do not have verbal communication skills requires commitment, focus and skill. This is challenging work that involves accepting, knowing and working alongside PWAD regardless of their actions and behaviour and proactively adopting a positive, non-judgemental stance. In relation to theories and practice frameworks I would describe this as the adoption of a palliative care approach (Scottish Partnership for Palliative Care, 2006) and all that is involved with this, but that this is combined with relationship centred care (Kitwood 1997, Nolan et al 2003, Tresolini and the Pew Fitzer Task Force 1994). A palliative care approach provides a framework to focus the delivery of care and ensure that key elements of need are addressed. 'Considering quality of life, good symptom control, a whole person approach, care for the person but also those that matter to them, respect for autonomy and choice and open and sensitive communication' (Scottish Partnership for Palliative Care, p10, 2006). The dementia palliative care needs assessment, conducted as part of this study, identified that this form of approach is appropriate for both PWAD and their carers as their needs fit with this model. New learning identified by the researcher, focused on the utilisation of relationship centred care as a way of implementing a palliative care approach. To use a simple domestic analogy, the palliative care approach could be described as the knitting pattern and relationship centred care as the knitting needles. A developing understanding of the perceptions, needs and experiences of PWAD and their carers shifted a focus on the need to develop relationships rather than focus on person centred approaches. The complexity of understanding a situation and giving appropriate care requires the involvement of the PWAD, family and the practitioners involved. Relationships with and between these groups can assist in understanding a situation and the provision of appropriate care and support.

As a researcher and practitioner, I developed an increased awareness and understanding of person centred care, however this was more related to limitations and challenges in the provision of this approach. The reasons for this were based on a new awareness of evidence and debate in literature specific to personhood and person centred care for PWAD (Adams 2005, Bartlett 2000). Experiences of hearing the voice of family carers had highlighted the necessity of looking, as far as possible, at the whole situation and to focus on the individual with dementia alone was a skewed approach. In the severe stages of the disease, a relationship centred approach could be argued as even more necessary, when verbal communication is lost and the resources of all those involved are required to plan and give appropriate care.

#### **8.4.2 The suitability of adopting a palliative care approach for PWAD and their carers**

As discussed above the dementia palliative care needs assessment conducted at the onset of this research, identified that the needs of PWAD and their carers could easily be identified and understood within a palliative care framework. Previous research would support this (McCarthy et al 1997, Hughes et al 2005).

The action phase of the research, where practice developments were undertaken in the assessment and management of pain and distress for PWAD and supporting carers, also very strongly identified real needs in this area and complexity in considering how to enhance service provision. Without doubt both of these are easily classified as palliative care issues and more research and practice development is required.

A focus on dementia awareness persisted with the action phase of the research. A gap was evident at the onset of the research, between what was identified in dementia care literature and what was evident in the practice of services participating in the action phase, particularly generic services such as the day centre. At the onset of the work I had not anticipated providing specific dementia care training, however a need existed to address this gap in

knowledge and practice, in accordance with the adoption of a palliative care approach for PWAD, this was entirely appropriate.

It can be argued that a palliative care approach, incorporating physical, social, psychological and spiritual aspects, whilst caring for people as individuals, using good communication and respecting autonomy and dignity (Scottish Partnership for Palliative Care, 2006), does provide an overarching care and support system appropriate for PWAD and their carers. As discussed previously and for the reasons provided, the place of family carers within a palliative care approach for PWAD would take a higher priority. Should any reframing of a palliative care approach for PWAD be undertaken, evidence from this research would suggest an increased emphasis on the carer, their support, knowledge and involvement. This would not be in conflict with the focus on the personhood of the PWAD, but rather support it through relationship centred care. Also as previously mentioned, utilising relationship centred care would be a process, particularly relevant to PWAD and their carers, that could enable the out working of a palliative care approach.

#### **8.4.3 Researcher as facilitator: introducing evidence into practice**

A further area of learning between the facilitator and dementia care practitioners was the introduction of a variety of assessment tools identified from research literature, such as the Revised Elderly Persons Disability Score (Fleming, 1994) the Disability Distress Assessment Tool (Regnard et al, 2006) and the Carers Checklist (The Mental Health Foundation, 1998). Finding these tools in literature and being able to discuss them and consider their practical application was valuable. The experience of this research was that a facilitator role was useful, particularly within the Day Care setting, as a social care organisation they had been self sufficient in developing their practice therefore had not benefited from someone with different expertise including knowledge of dementia care research. This is consistent with a core element of action research, namely bridging the gap between research and practice (Hart and Bond, 1995).



#### **8.4.4 Researcher as facilitator: the importance of practice development approaches and reflective practice.**

It could be argued that my practice development facilitation and communication skills, rather than palliative care knowledge and skills, were what was required in terms of shared learning and enabling change. Holding reflection and action meetings and conducting action learning were processes that made staff stop, think and reflect on their practice. All staff were quick to move to change without careful consideration of the reasons for this and considering how to proceed. Considering and planning distinct processes such as identifying local need, considering evidence and potential practice changes, then implementing and evaluating these, required greater emphasis. Reflective processes facilitated a deeper understanding enabling a different way of working. This is consistent with Cockburn and Trentham (2002) and Meyer (2000) views that all elements of AR should involve democratic collaboration, namely information sharing, systematic inquiry, reflection and action, with the expected outcome of meaningful social change.

#### **8.4.5 Inclusion of PWAD, carers and staff facilitated learning, understanding and action**

Further key learning processes arose from the direct inclusion of PWAD, their carers and staff in this research. The research data highlighted that increased awareness and understanding of dementia care issues occurred as a result of involving PWAD, carers and staff. Within the day care setting and the community hospital this was very evident, awareness of the struggles of carers and an in-depth understanding of their situation was integral to staff motivation and engagement in practice development activity. This is consistent with participatory action research theories that highlight the essential component participants bring to the direction and learning of the research experience (Livesey and Challender, 2002).

#### **8.5 Research aim four: In relation to the assessment and management of pain and distress for PWAD and supporting carers of PWAD, determine**

## **potential future implications for practice development and service delivery.**

In this section I will concentrate on discussing the implications for practice development, as service delivery implications will be identified in the following chapter, chapter nine recommendations from the research.

### **8.5.1 The collective influence of services working together**

A key learning point from this action research was the collective influence of services and participants working together to facilitate strategic change. The parent project had developed a network of people and services, for example those working on the project steering group and those from participating services. This collective group had an awareness of systems and processes but also relationships with individuals from key services that enabled a strong opportunity to influence. These were key factors in the development of a strategic group for PWAD in West Lothian. There was benefit in bringing different services together to jointly develop practice, particularly development of a strategic nature. This finding was consistent with the notion of social change through empowerment (Karim, 2001). Processes such as action learning enabled practitioners to consider their collective influence and plan ways of influencing those with strategic responsibilities.

### **8.5.2 The positive impact of shared reflection, learning and action**

Furthermore the processes of reflection in action research, in particular action learning, had allowed participants the space to collectively reflect and consider ways of influencing situations. Reflections taken from action learning, identified that when Jean was presenting and considering how to influence the development of a strategic West Lothian group, this had a direct impact on my own analysis and consideration of potential action. This demonstrated a situation of both individual and shared reflection, learning and action. The combination of these factors enabled the positive outcome of a strategy group being established. The out working and development of the strategy group continued after the work of this research and therefore the ultimate outcome of enhancing services for PWAD and their carers remains to be identified. This

supports the view that individuals learn with and from each other by working on real problems and reflecting on their own experiences...The process helps to take an active stance towards life', (McGill and Beaty, p11, 2001).

### **8.5.3 Questioning the usefulness of conducting a distinct baseline understanding phase with participating services**

It was useful for the researcher to have a realistic working knowledge of each service prior to engagement in the action phase of the research. The baseline data gathering phase facilitated this understanding. However from this research experience, this could have been achieved in a shorter time frame whilst beginning activity on the action phase. I felt the baseline understanding phase took too long and the same result could have been achieved without this distinct data-gathering period. It is worth noting that despite achieving a working knowledge and realistic understanding of Meadow Day Centre, the carer support interventions were too ambitious and did not consider appropriately the limited number of available carers associated with this service. It is important not to be overly critical, however it could be argued that this outcome should have been avoided if the service was reasonably understood. In future action research activity I would lessen the focus and time spent on the notion of developing a baseline understanding (Coghlan and Brannick, 2005).

### **8.5.4 The importance of time and researcher / participant relationship when developing practice**

Predictably two other factors were key when considering practice development, these were the relationship between the researcher and participants and the need for time to enable an understanding of the relevant issues amongst all participants and to allow changes to practice. In terms of the research relationship, key aspects highlighted in the data for example from the evaluation of action learning from practitioners, included: the benefit of credibility, providing a balance of support and challenge, modelling of appropriate behaviours for example critical questioning and relationships which were sustained over the period of the research. Sensitivity but also fun appeared to be important.

The action phase of this research lasted 25 months. Working with a team, who do not always work together due to shift patterns requires time. Ensuring issues such as completing training for all staff and for new ways of working to become embedded into ordinary practice took time. In my own reflections on this subject during the course of this research, I consistently underestimated the time necessary to achieve such changes. It is important to acknowledge the implications of shortages of staff, staff sickness and other work streams, which impacted on the time it took to conduct this research. Despite these issues being reported in other action research projects, there was an element of needing to learn whilst experiencing these situations (Meyer 1993, Karim 2001).

#### **8.5.5 Contribution of this research to new knowledge**

In accordance with the needs of PWAD identified through the West Lothian palliative care needs assessment; a palliative care approach would be an appropriate model of care to adopt.

This research has identified that the DisDAT is an appropriate tool for use with PWAD and the assessment process is consistent with the practical application of relationship centred approach to care. The assessment of distress is a complex process, for PWAD it was clinically appropriate to consider a broader notion of distress before focussing on pain. Group assessment and decision-making processes by nurses were beneficial when using the DisDAT, assessing the behaviours of PWAD then identifying their meaning. The term distress required clarification by the nursing team.

A number of factors were identified which cumulatively meant carers of PWAD experienced restrictions to accessing support and that their needs were hidden. The social façade of the PWAD, a lack of communication between health and social care services and the absence of an identified person with ongoing responsibility to support carers. Ongoing care of the PWAD took precedence

over accessing support and the preferences of the PWAD dictated what support was available to the carer.

## **Chapter 9**

### **Recommendations from research**

#### **9.1 Introduction to chapter**

This chapter will present recommendations from this research. Recommendations will be made in respect of three main areas: in section 9.2 general palliative care for PWAD, in section 9.3 the assessment and management of distress and pain for PWAD and in section 9.4 supporting family carers. Due to the discussion of these issues in previous chapters these recommendations are deliberately presented briefly.

#### **9.2 Palliative care for PWAD**

These recommendations relate to the broad notion of service providers recognising and adopting a palliative care approach for PWAD and their carers. Evidence to support these recommendations primarily arose from the outcomes from the needs assessment process. Key priorities identified from the needs assessment were: Providing care that is person centred, managing pain and other symptoms for PWAD, supporting family carers, the provision of respite care, equity of access to services and finally the development of a strategic dementia group in West Lothian.

The research has demonstrated that:

- It would be beneficial for policy makers within government and NHS Boards, to consider implementing a process where there is ongoing access to a dedicated professional, from the point of diagnosis of a dementia illness. This could enable the application of a palliative care approach and effective utilisation of services, according to need, as the dementia journey progresses, further research is necessary.
- Adopting relationship centred care, actively and consistently involving PWAD, their carers and staff, would provide a dementia appropriate way of implementing a palliative care approach.

- Joint collaboration between specialist palliative care services and dementia care should focus their training and practice development activities on generic services providing care for PWAD and their carers, such as care homes, continuing care settings and day care settings.

### **9.3 Assessment and management of distress and pain for PWAD**

These recommendations have been developed from the evidence gathered from the implementation of assessment tools for pain and distress for PWAD. Key findings were: how complex it was to interpret and understand the distressed behaviour of a person with advanced dementia who has severe communication difficulties; the DisDAT proved to be an appropriate tool for use with PWAD; the term distress itself required debate and clarification amongst nursing staff; completing the DisDAT required a group of nurses to debate and then agree assessment findings; it was considered beneficial to consider a broader notion of distress rather than initially focus on pain.

The research has demonstrated that:

- The DisDAT is an appropriate tool to use for PWAD who have communication difficulties.
- The DisDAT provides a person centred approach to assessment of PWAD, policy makers should consider how this tool could be practically implemented within a range of care settings.
- Although the DisDAT offers a person centred approach to assessment, relationship centred care was identified as a valuable approach to completing the assessment.
- Potentially the optimal setting for use of the DisDAT would be continuing care or where people are cared for a period of months, further academic research is required to determine the appropriateness of the tool in a variety of care settings for PWAD.

- It is necessary to manage the expectations of staff, the DisDAT provides a comprehensive assessment of distress and contentment but clinical decisions for PWAD remain complex and difficult

#### **9.4 Supporting family carers of PWAD**

These recommendations arose from evidence gathered working with Meadow Day Centre and the carer support interventions they implemented and evaluated. There were benefits to implementing formal carer assessment and a need existed for individual, flexible carer support interventions. The ongoing provision of care for the PWAD took precedence over accessing support activities and the physical and psychological affects of caring, negatively impacted on ability to participate in support interventions. The behaviour and preferences of the PWAD became key factors in the services that were available to carers. The Needs of carers were hidden to service providers due to: services for PWAD in West Lothian being disconnected, the positive social façade of the PWAD and the absence of ongoing, 'live' access to professionals to guide and support carers

- Support interventions should be flexible and based on the needs of individual carers.
- Service providers should ensure that care arrangements for the PWAD should be available enabling carers to attend support activities.
- It would be important that policy makers initiate the availability of a range of flexible respite options to ensure individual needs can be met and carers have access to planned breaks from caring.
- A formal, comprehensive assessment, such as the Carers Checklist, can identify areas of need and identify individual support required.
- In respect of strategic Managers and Directors within practice, Dementia care services must develop an active joined up approach where contributions from all agencies are valued and shared and therefore the understanding of individual approaches to care are optimised.



- As stated in 9.2, ongoing access to a dedicated professional, from the point of diagnosis of a dementia illness, would enable the application of a palliative care approach and utilisation of services according to need as the dementia journey progresses. This could provide a key support contact and service to carers of PWAD. The adoption of relationship centred care would be a necessary way of working for this professional.

## List of References

- Abbey J De Bellis A Piller N Esterman A Giles L Parker D Lowcay B (2002) Abbey Pain Scale Dementia Care Australia Pty Ltd [www.dementiacareaustralia.com](http://www.dementiacareaustralia.com)
- Adams T (1996) Kitwood's approach to dementia and dementia care: a critical but appreciative view Journal of Advanced Nursing 23 948-953
- Adams T (2005) From person centred care to relationship centred care Generations Review 15 1 4-7
- Addington-Hall J Higginson I (2001) Palliative Care for Non Cancer Patients Oxford Oxford University Press
- Ahronheim J Morrison S Baskin S Meier D (1996) Treatment of the dying in the acute care hospital: advanced dementia and metastatic cancer Archives of Internal Medicine 156 2094-2100
- Albinsson L Strang P (2002) A palliative approach to existential issues and death in end stage dementia Journal of Palliative Care 18 3 168-174
- Albinsson L Strang P (2003) Differences in supporting families of dementia patients and cancer patients: a palliative perspective Palliative Medicine 17 359 - 367
- Alzheimers Society (2004) Policy positions available at <http://www.alzheimers.org.uk/news>
- Alzheimer Scotland Action on Dementia (2005) Letting go without giving up JMK Printers Linlithgow
- Alzheimer Scotland Action on Dementia (2006) Alzheimer Scotland welcomes research on risk reduction factors for dementia Available at <http://www.alzscot.org> (accessed 9 August 2006)
- American Geriatric Society (1998) Panel on chronic pain on older adults: The management of chronic pain on older persons Journal of the American Geriatric Society 46 635-651
- Annerstedt L Elmstahl S Ingvad B Samuelsson S (2000) Family caregiving in dementia: an analysis of the caregiver's burden and the breaking point when home care becomes inadequate Scandinavian Journal of Public Health 28 (1) 23-31
- Ansari W Phillips C Hammick M (2001) Collaboration and partnerships: developing the evidence base Health and Social Care in the Community 9 (4) 215-227

Archibald C (2002) People with dementia in acute hospital settings Dementia Services Development Centre Stirling

Argyris C Schon D (1991) Participatory action research and actions science compared: a commentary In Whyte W Ed (1991) Participatory Action Research Sage Thousand Oaks California

Askham J (1998) Supporting caregivers of older people: An overview of problems and priorities. Paper presented at the World Congress of Gerontology, Adelaide.

Atkins S Murphy K (1994) Reflective practice Nursing Standard 8 (39) 49-54

Australia Institute of Health and Wellbeing (2005) Residential aged care in Australia: 2002-2003: a statistical review Aged Care Statistics Series 18 AIHW Canberra

Axford N Green V Kalsbeek A Morpeth L Palmer C (2009) Measuring children's needs: how are we doing? Child and Family Social Work 14 243-254

Badger T (2000) Action research, change and methodological rigour Journal of Nursing Management 8 (4) 201-207

Barnes M Warren L (1999) Paths to empowerment The Policy Press Bristol

Bartlett R (2000) Dementia as a disability can we learn from disability studies and theory? Journal of Dementia Care Sept/Oct 33-36

Bartol M (1989) Story in nursing practice Nursing and Health Care 10 8 564-565

Beavis D Simpson S Graham I (2002) A literature review of dementia care mapping: methodological considerations and efficacy Journal of Psychiatric and Mental Health Nursing 9 725-736

Bell C Araki S Neumann P (2001) The association between caregiver burden and caregiver health-related quality of life in Alzheimer Disease Alzheimer Disease and Associated Disorders 15 3 129-136

Bender M (2003) Explorations in dementia Jessica Kingsley Publications London

Birch D Draper J (2008) A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia Journal of Clinical Nursing 17 1144-1163

Binnie A Titchen A (1999) Freedom to Practice: The Development of Patient-centred Nursing Butterworth Heinemann Oxford

- Boland M Daly L Staines A (2007) Methodological issues in inclusive intellectual disability research: a health promotion needs assessment of people attending Irish disability services Journal of Applied Research in Intellectual Disabilities 21 199-209
- Bowling A (1997) Research Methods in Health Open University Press Buckingham
- Boyd E Fales A (1983) Reflective learning: the key to learning from experience Journal of Humanistic Psychology 23 (2) 99-117
- Boyle A (2005) NICE draft guidance on AD: a pandora's box? Geriatric Medicine March 11
- Brodaty H Green A Koschera A (2003) Meta-analysis of psychosocial interventions for caregivers of people with dementia Journal of American Geriatric Society 51 657 – 664
- Brockopp D Warden S Colclough G Brockopp G (1996) Elderly people's knowledge of and attitudes to pain management British Journal of Nursing 5 556-562
- Budewig K Crawford F Hamlet N Hanlon P Murie J Ogilvie D (2004) Obesity in Scotland: Why diets, doctors and denial don't work [www.obesityscotland.org.uk](http://www.obesityscotland.org.uk)
- Buijsen H (2005) The simplicity of dementia: a guide for family and carers Jessica Kingsley Publishers London
- Care Commission (2003) National Care Standards Hospice Care The Stationary Office Edinburgh
- Carr W Kemmis S (1986) Becoming critical: Education, Knowledge and Action Research Falmer press London
- Carradice A Beail N Shankland M (2003) Interventions with family caregivers for people with dementia: efficacy problems and potential solution Journal of Psychiatric and Mental Health Nursing 10 307 -315
- Carter T Beresford P (2000) Age and change, models of involvement for older people Joseph Rowntree Foundation York
- Chandler D Torbert W (2003) Transforming inquiry and action by interweaving 27 flavors of action research Action Research 1 (2) 133-152
- Clarke A Hanson E Ross H (2003) Seeing the person behind the patient: enhancing the care of older people using a biographical approach Journal of Clinical Nursing 12 697-706

Clark P (1996) Communication between provider and patient: values, biography, and empowerment in clinical practice Ageing and Society 16 (6) 747-774

Clinical Standards Board for Scotland (2002) Specialist Palliative Care Standards Clinical Standards Board for Scotland

Closs S (1996) Pain and elderly patients: a survey of nurses' knowledge and experience Journal of Advanced Nursing 23 237-242

Cockburn L Trentham B (2002) Participatory action research: Integrating community occupational therapy practice and research The Canadian Journal of Occupational Therapy 69 1 20-30

Coghlan D and Casey M (2001) Action research from the inside: issues and challenges in doing action research in your own hospital Journal of Advanced Nursing 35 (5) 674-682

Coghlan D and Brannick T (2005) Doing action research in your own organisation Sage London

Cohen-Mansfield J Lipson S (2002a) Pain in cognitively impaired nursing home residents: how well are physicians diagnosing it? Journal of the American Geriatric Society 50 1039-1044

Cohen-Mansfield J Creedon M (2002b) Nursing staff members' perceptions of pain indicators in persons with severe dementia The Clinical Journal of Pain 18 64-73

Cook A Niven C Downs M (1999) Assessing the pain of people with cognitive impairment International Journal of Geriatric Psychiatry 14 421-425

Cunningham C (2006) Managing pain in patients with dementia in hospital Nursing Standard 20 46 54-58

Cutson T (2001) Management of pain in the older adult Clinics in Family Practice 3 3 1-14

Davies S Nolan M Brown J Wilson F (1999) Dignity on the Ward: Promoting Excellence in Care Help the Aged London

Davies S Nolan M (2004) Making the move: relatives experiences of the transition to a care home Health and Social Care in the Community 12 6 517-526

Day K Carreon D Stump C (2000) Therapeutic design of environments for people with dementia: a review of the empirical research The Gerontologist 40 397-416

Dewar B (2005) Moving upstream together (training material) Edinburgh

Dewing J (2004) Concerns relating to the application of frameworks to promote person-centredness in nursing older people International Journal of Older People Nursing in association with Journal of Clinical Nursing 13 (3D) 31-38

DeWolf Bosek M Lowry E Lindeman D Burck R Gwyther L (2003) Promoting a good death for persons with dementia in nursing facilities JONA's Healthcare Law, Ethics, and Regulation 5 2 34-41

Downs M Small N Froggatt K (2006) Explanatory models of dementia care: links to end of life care International Journal of Palliative Nursing 12 5 209-213

Doyle D Hanks G MacDonald N (1998) Oxford Textbook of Palliative Medicine 2<sup>nd</sup> Ed Oxford University Press Oxford

Ellershaw J Wilkinson S Ed (2003) Care of the Dying A pathway to excellence Oxford University Press Oxford

Ellis L Crookes P (1998) Philosophical and theoretical underpinnings of research In Crookes P Davies Eds Research into Practice Baillière Tindall London

Evans B (2002) Improving palliative care in the nursing home: from a dementia perspective Journal of Hospice and Palliative Nursing 4 2 91-99

Eve A Smith A Tebbit P (1997) Hospice and palliative care in the UK 1994-5 including a summary of trends 1990-5 Palliative Medicine 11 31-43

Evers M Purohit D Perl D Khan K Marin D (2002) Palliative and aggressive end of life care for patients with dementia Psychiatric Services 53 609-613

Feil N (1992) Validation therapy with late onset dementia patients IN Jones G Mieson B Care-giving in dementia Routledge London 199-218

Ferrell B Ferrell B Osterweil D (1990) Pain in the nursing home Journal of the American Geriatric Society 38 409-414

Ferrell B Ferrell B Rivera L (1995) Pain in cognitively impaired nursing home patients Journal of Pain and Symptom Management 10 8 591-598

Finifter D Jensen C Wilson C Koenig B (2005) A comprehensive, multitiered, targeted community needs assessment model methodology, dissemination, and implementation Family and Community Health October - December 28 293-306

Fitzgerald M (1994) Theories of reflection for learning in Palmer A Burns S Bulman C Eds Reflective Practice in Nursing Blackwell Scientific Oxford

- Fleming R (1994) The Revised Elderly Persons Disability Scale: Validity, Reliability and Usefulness. Available from the Dementia Services Development Centre, Stirling University, and Web: [www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk)
- Frampton M (2003) Experience assessment and management of pain in people with dementia Age and Ageing 32 3 248
- Froggatt K Hoult L (2002) Developing palliative care practice in nursing and residential care homes: the role of the clinical nurse specialist Journal of Clinical Nursing 11 802-808
- Froggatt K Payne S (2006) A survey of end of life care in care homes: issues of definition and practice Health and Social Care in the Community 14 4 341-348
- Gibbs G (1988) Learning by doing: A guide to teaching and learning methods Oxford Further Education Unit Oxford Polytechnic
- Gibson F (1998) Reminiscence and Recall: A Guide to Good Practice 2<sup>nd</sup> Ed London Age Concern
- Gibson F (2004) The Past in the Present: using Reminiscence in Health and Social Care Baltimore MD Health Professions Press
- Gilleard C (1984) Living with dementia Groom Helm London
- Gow J Gilhooly M (2003) Risk factors for dementia and cognitive failure in old age NHS Scotland Glasgow
- Grad J d'Alarcon Sainsbury P (1965) An evaluation of the effects of caring for the aged at home in Psychiatric Disorders in the Aged WPA Symposium Geigy Manchester
- Greenwood J (1994) Action research: a few details, a caution and something new Journal of Advanced Nursing 20 13-18
- Gwyther L (2001) Family caregivers and long term care: Caring together Alzheimer's Care Quarterly Winter
- Hagen I Cahill S Begley E Macijauskiene J Gilliard J Jones K Topo P Saarikalle K Holthe T Duff P (2005) Assessment of usefulness assistive technologies for people with dementia IN Pruski A Knops H (Eds) Assistive technology: from virtuality to reality Amsterdam IOS Press
- Hall G Buckwalter K (1987) Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease Archives of Psychiatric Nursing 1 6 399-406

Hart E Bond M (1995) Action research for health and social care Open University Press Buckingham

Health Education Board for Scotland (2003) Coping with dementia: a handbook for carers NHS Health Scotland

Hearn J Higginson I (1998) Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review Palliative Medicine 12 317-332

Herr K (2002) Chronic pain: Challenges and assessment strategies Journal of Gerontological Nursing 28 1 20-27

Herr K Decker S Bjoro K (2004) State of the art review of tools for assessment of pain in nonverbal older adults University of Iowa keela-herr@uiowa.edu

Hertogh C (2005) Book review: Ethical Foundations of Palliative Dementia Care Alzheimers Disease and Associated Disorders 19 3 159-160

Higgs P (2005) A view from medical sociology Generations Review 15 1 12-14

Hinman M Heyl D (2002) Influence of the Eden Alternative on the functional status of nursing home residents Occupational Therapy in Geriatrics 20 1-20

Hockley J (2002) Organisational structures for enhancing standards of palliative care IN Hockley J Clark D (Eds) Palliative care for older people in care homes Open University Press Buckingham

Hockley J Dewar B Watson J (2004) Developing quality end of life care in eight independent nursing homes through the implementation of an integrated care pathway for the last days of life www.stcolumbashospice.org.uk

Hockley J Froggatt K (2006) The development of palliative care knowledge in care homes for older people: the place of action research Palliative Medicine 20 835-843

Hope K (1998) Starting out with action research Nurse Researcher 6 (2) p16-26

Hope K Waterman H (2003) Praiseworthy pragmatism? Validity and action research Journal of Advanced Nursing 44 (2) 120-127

Horgas A Tsai P (1998) Analgesic drug prescription and use in cognitively impaired nursing home residents Nursing Research 47 235-242

Hughes J Robinson L Volicer L (2005) Specialist palliative care in dementia British Medical Journal 330 7482 57-58



- Hurley A Volicer B Hanrahan P Houde S Volicer V (1992) Assessment of discomfort in advanced Alzheimer patients Research in Nursing and Health 15 369-377
- Johnson M (1976) That was your life: a biographical approach to later life IN An Ageing Population Carver C Liddiard P Eds Hodder and Stoughton Sevenoaks
- Karim K (2001) Assessing the strengths and weaknesses of action research Nursing Standard 15 (26) 33-35
- Katz J Komaromy C Sidell M (1999) Understanding palliative care in residential and nursing homes International Journal of Palliative Nursing 5 2 58-64
- Katz J Peace S (2003) End of life in care homes: a palliative care approach Oxford University Press Oxford
- Katz J (2005) Palliative care in residential care facilities: a brief review International Journal of Palliative Nursing 11 3 130-131
- Keene J Hope T Fairburn C Jacoby R (2001) Death and dementia International Journal of Geriatric Psychiatry 16 969-974
- Kemmis S (1982) The Action Research Reader 2<sup>nd</sup> Ed Deakin University Press Australia
- Kemmis S McTaggart R Eds (1998) The Action Research Planner Deacon University Press Victoria
- Killick J Allan K (2001) Communication and the care of people with dementia Open University Press Buckingham
- Killick J Allan K (2005) The good sunset project: quality of life in advanced dementia Journal of Dementia Care Nov / Dec issue 22-24
- King N Thomas K Martin N Bell D Farrell S (2005) 'Now nobody falls through the net': practitioners perspectives on the Gold Standards Framework for community palliative care Palliative Medicine 19 619-627
- Kitwood T Bredin K (1992) A new approach to the evaluation of dementia care Journal of Advances in Health and Nursing Care 1 41-60
- Kitwood T (1994) The Validation Breakthrough (book review) Journal of Dementia Care 2 6 29-30
- Kitwood T (1997) Dementia reconsidered: the person comes first Open University Press Buckingham

- Kovach C Weissman D Griffie J Muchka S (1999) Assessment and treatment of discomfort for people with late stage dementia Journal of pain and symptom management 18 6 412-419
- Kovach C Griffie J Muchka S Noonan P Weissman D (2000) Nurses perceptions of pain assessment and treatment in the cognitively impaired: it's not a guessing game Clinical Nurse Specialist 14 5 215-220
- Kovach C Noonan P Griffie J Muchka S Weissman D (2002) The assessment of discomfort in dementia protocol Pain Management Nursing 3 1 16-27
- Krullewitch H London M Skakel V Lundstedt G Thomasen H Brummel-Smith K (2000) Assessment of pain in cognitively impaired older adults: a comparison of pain assessment tools and their use by non-professional caregivers Journal of the American Geriatric Society 48 1607-1611
- Lathlean J (1996) Ethical dimensions of action research In de Raeye L Ed Nursing Research: an Ethical and Legal Appraisal Bailliere Tindall London
- Lefebvre-Chapiro S (2001) The DOLOPLUS ® 2 scale – evaluating pain in the elderly European Journal of Palliative Care 8 5 191-194
- Lewin C (1946) Action research and minority problems Journal of Social Issues 2 34-46
- Little M Bullock R Madge J Arruabarrena I (2002) How to develop needs led evidence based services MCC Building Knowledge for Integrated Care 10 28-32
- Livesey H Challender S (2002) Supporting organisational learning: a comparative approach to evaluation in action research Journal of Nursing Management 10 167-176
- Lothian Palliative Care Guidelines Development Group (2006) Lothian Palliative Care Guidelines \_Edinburgh
- Maas M Reed D Park M Specht J Schutte D Kelley L Swanson E Tripp-Reimer T Buckwalter K (2004) Outcomes of family involvement in care intervention for caregivers of individuals with dementia Nursing Research 53 2 76 - 86
- Macdonald N (1991) Palliative care-the fourth phase of cancer prevention Cancer Detection and Prevention 15 253-255
- Markowitz J Gutterman E Sadik K Papadopoulos G (2003) Health related quality of life for caregivers of patients with Alzheimer Disease Alzheimer Disease and Associated Disorders 17 209-214

MacDonald N (1998) The interface between oncology and palliative medicine IN Doyle D Hanks G MacDonald N Oxford Textbook of Palliative Medicine 2<sup>nd</sup> Ed Oxford University Press Oxford

Marshall M (2001) The challenge of looking after people with dementia British Medical Journal 323 August 410-411

McCance T (2003) Caring in nursing practice: the development of a conceptual framework Research and Theory for Nursing Practice: An International Journal 17 (2) 101-116

McCarthy M Addington Hall J Altmann D (1997) The experience of dying with dementia International Journal of Geriatric Psychiatry 12 404-409

McCaffery M Beebe A (1989) Pain: Clinical Manual for Nursing Practice MO Mosby St. Louis

McClea W (2000) Practice guide for pain management for people with dementia in institutional care The Dementia Services Development Centre Stirling

McCormack B (2004) Person-centredness in gerontological nursing: an overview of the literature Journal of Clinical Nursing 13 3a 33-38

McCormack B McCance T (2006) Development of a framework for person-centred nursing Journal of Advanced Nursing 56 5 1-8

McGarry Logue R (2003) Maintaining family connectedness in long term care: an advanced practice approach to family centred nursing homes Journal of Gerontological Nursing 26 6 24

McGuire D (1992) Comprehensive and multidimensional assessment and measurement of pain Journal of Pain and Symptom Management 7 5 312-319

McGill I Beaty L (2001) Action Learning a guide for professional, management and educational development 2<sup>nd</sup> Ed Kogan Page Limited London

McNiff J (1988) Action research: Principles and practice Macmillan Education London

Meyer J (1993) New paradigm research in practice: the trials and tribulations of action research Journal of Advanced Nursing 18 1066-1072

Meyer J Spilsbury K Prieto J (1999) Comparison of findings from a single case in relation to those from a systematic review of action research Nurse Researcher 7 (2)

Meyer J (2000) Using qualitative methods in health related action research British Medical Journal 320 January 178-181

Miller L Nelson L Mezey M (2000) Comfort and pain relief in dementia Journal of Gerontological Nursing September 33-40

Mindell A (1999) Coma: a healing journey, a guide for family, friends and helpers Press Portland Oregon

Mobily P Herr K (2001) Pain in Maas M Buckwalter K Hardy M Tripp-Reimer T Titler M Specht J Nursing Care of Older Adults: Diagnosis, Outcomes and Interventions 455-475 MO Mosby St. Louis

Morgan K (2005) Living with dementia: then and now Generations Review 15 1 2-3

Morris C (2004) Personal construct psychology and person centred care IN Care giving in dementia: research and applications 3 Jones G Miesen B Brunner-Routledge London

Morrison R Sui A (2000) A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture Journal of Pain and Symptom Management 19 4 240-248

Morrison R Sui A (2000) Survival in end stage dementia following acute illness Journal American Medical Association 284 47-52

Murray SA Kendall M Boyd K Sheikh A (2005) Illness trajectories and palliative care British Medical Journal 330 1007-1011

National Alcohol Information Resource, Information Services Division (2004) Alcohol Statistics Briefing, NHS National Services Scotland

NHS Education Scotland (2006) A realist synthesis of evidence relating to practice development: final report to NHS Education Scotland and NHS Quality Improvement Scotland NHS Education Scotland

NHS Health Scotland (2003) Needs assessment report Dementia and Older People NHS Health Scotland

NHS Lothian (2006) Improving Care Investing in Change Available at [http://www.nhsllothian.scot.nhs.uk/icic/strategic\\_programme/report-publication\\_version.pdf](http://www.nhsllothian.scot.nhs.uk/icic/strategic_programme/report-publication_version.pdf) (accessed 9 August 2006)

Nolan M Ingram P Watson R (2002) Working with family caregivers of people with dementia Dementia 1 1 75-93

Nolan M Lundh U Grant G Keady J (2003) Partnerships in family care Open University Press Buckingham

Nolan M Davies S Brown J Keady J Nolan J (2004) Beyond 'person-centred' care: a new vision for gerontological nursing International Journal of older people nursing 13 (3a) 45-53

Nolan M Brown J Davies S Nolan J Keady J (2006) The SENSES Framework :Improving care for older people through a relationship-centred approach The University of Sheffield

Norman R (2002) Research notes: Inclusion of people with dementia in research studies Nursing Standard 17 2 p21

Packer T (2000) Does person centred care exist? Journal of dementia care 8 3 19-21

Parahoo K (1997) Nursing Research Principles, Process and Issues Macmillan Press Ltd. Hampshire

Parmalee P Smith B Katz I (1993) Pain complaints and cognitive status among elderly institution residents Journal of the American Geriatric Society 41 523-530

Peace S Ed (1999) Involving older people in research 'An amateur doing the work of the professional' Centre for Policy on Ageing Open University Press London

Phillips J Davidson P Jackson D Kristjanson L Daly J Curran J (2006) Residential aged care: the last frontier for palliative care Journal of Advanced Nursing 55 4 416-424

Poole J (2006) The Alzheimer's Society guide to the dementia care environment London Alzheimer's Society

Pratt R in Wilkinson H Ed (2002) The perspectives of people with dementia: research methods and motivations Jessica Kingsley Publishers London

Pulsford D (1997) Therapeutic activities for people with dementia – what, why...and why not? Journal of Advanced Nursing 26 704-709

Reason P (1988) Ed Human enquiry in action: developments in new paradigm research Sage London

Reason P Torbet W (2001) The action turn: toward a transformational social science Concepts and Transformations 6 (1) 1-37

Reason P Bradbury H (2008) Action Research Participative Inquiry and Practice Second Edition Sage Publications London

Regnard C Reynolds J Watson B Matthews D Gibson L Clarke C (2006) Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT) Journal of Intellectual Disability Research 1-6

Rolfe G (1995) An action research project to develop and evaluate the role of an advanced nurse practitioner in dementia Journal of Clinical Nursing 4 (5) 289-293

Rolfe G (1996) Going to extremes: action research, grounded practice and the theory practice gap in nursing Journal of Advanced Nursing 24 1315-1320

Rolfe G Freshwater D Jasper M (2001) Critical reflection for nursing and the helping professions Palgrave Macmillan Hampshire

Russell V Proctor L Moniz E (1989) The influence of a relative support group on carers' emotional distress Journal of Advanced Nursing 14 863-867

Roth M Huppert F Tym E Mountjoy C (1988) CAMDEX1: The Cambridge examination for Mental Disorders of the Elderly Cambridge Cambridge University Press

Sachs G Shega J Cox-Haley D (2004) Barriers to excellent end of life care for patients with dementia Journal of General Internist Medicine 19 1057-1063

Sampson E Ritchie C Lia R Raven P Blanchard M (2006a) A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia International Psychogeriatrics 17 31-40

Sampson E Ritchie C Lai R Raven P ca M (2006b) Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study Age and Ageing 35 187-189

Sanford J (1975) Tolerance of debility in elderly dependants by supporters at home: its significance for hospital practice British Medical Journal 3 471-473

Saunders C (1998) Foreward In Doyle D Hanks G MacDonald N (1998) Oxford Textbook of Palliative Medicine 2<sup>nd</sup> Ed Oxford University Press Oxford

Scanland S Emershaw L (1993) Reality orientation and validation therapy: dementia, depression and functional status Journal of Gerontological Nursing 19 6 7-11

Scherder E Oosterman J Swaab B (2005a) Recent developments in pain in dementia British Medical Journal 330 7489 461-464

Scherder E Manen F (2005b) Pain in alzheimer's disease: nursing assistants' and patients' evaluations Journal of Advanced Nursing 52 2 151-158

Scottish Carers Alliance Coalition of carers in Scotland Carers Scotland the voice of carers The Princess Royal Trust for Carers (2005) Joint briefing Care 21: The future of unpaid care in Scotland Scottish Carers Alliance

Scottish Executive (2000) Our National Health Scottish Executive Edinburgh

Scottish Executive (2004) Template for delivering dementia services Scottish Executive Edinburgh

Scottish Executive (2005a) Delivering for health Scottish Executive Edinburgh

Scottish Executive (2005b) The future of unpaid care in Scotland OPM London

Scottish Executive (2006) Delivering care enabling health Scottish Executive Edinburgh

Scottish Executive Health Department (2004) Overcoming the obstacles to the improvement of dementia care, report of the Scottish Executive and Alzheimer Scotland short life working group Scottish Executive

Scottish Intercollegiate Guidelines Network (2000) SIGN 44 Control of Pain in Patients with Cancer Scottish Intercollegiate Guidelines Network Edinburgh

Scottish Intercollegiate Guideline Network (2006), Guideline 86: Management of patients with dementia SIGN Edinburgh

Scottish Government (2008a) Leading Better Care: Report of the Senior Charge Nurse Review and Clinical Quality Indicators project [www.scotland.gov.uk/publications/2008/05/30104057/0](http://www.scotland.gov.uk/publications/2008/05/30104057/0)

Scottish Government (2008b) Better together: Scottish Government Edinburgh

Scottish Partnership for Palliative Care (2006) Making good care better: National practice statements for general palliative care in adult care homes in Scotland Scottish Partnership for Palliative Care Edinburgh

Scottish Partnership for Palliative Care (2006) Joined up thinking Joined up care 'Increasing access to palliative care for people with life threatening conditions other than cancer Scottish Partnership for Palliative Care Edinburgh

Sengstaken E King S (1993) The problems of pain and its detection among geriatric nursing home residents Journal of the American Geriatric Society 41 541-544

Shega J Levin A Hougham G Cox-Haley D Luchins D Hanrahan P Stocking C Sachs G (2003) Palliative Excellence in Alzheimer Care Efforts (PEACE) Palliative Excellence in Alzheimer Care Efforts : A program description Journal of Palliative Medicine 6 2 315-320

Sidell M Katz J Komaromy C (1997) Death and dying in residential and nursing homes for older people Report to the Department of health

Sidell M Komaromy C (2003) Who dies in care homes for older people? IN Katz J Peace S Eds End of life care in care homes: a palliative care approach Oxford University Press Oxford

Small N Froggatt K Downs M (2007) Living and Dying with Dementia: Dialogues about Palliative Care Oxford Oxford University Press

Smith M (2005) Pain assessment in nonverbal older adults with advanced dementia Perspectives in Psychiatric Care 41 3 99-113

Snow A Weber J O'Malley K Cody M Beck C Bruera E Ashton C Kunik M (2004) NOPPAIN: a nursing assistant administered pain assessment instrument for use in dementia Dementia and Geriatric Cognitive Disorders 17 240-246

South East Scotland Cancer Network (2006) Annual report South East Scotland Cancer Network

Spector A Davies S Woods B Orrell M (2000) Reality orientation for dementia: A systematic review of the evidence of effectiveness from randomised controlled trials The Gerontologist 40 2 206-212

Stewart S McMurray J (2002) Palliative care for heart failure British Medical Journal 325 915-916

The Alzheimers Society (2004) Policy position: Withdrawing and withholding treatment /palliative care  
[www.alzheimers.org.uk/News\\_and\\_campaigns/Policy\\_watch/palliativecare.htm](http://www.alzheimers.org.uk/News_and_campaigns/Policy_watch/palliativecare.htm)

The Mental Health Foundation (1998) The Carers Checklist The Mental Health Foundation

The National Council for Palliative Care (2006) National survey of patient activity data for specialist palliative care services Hobbs Printers Ltd London

The Scottish Office Scottish Partnership Agency for Palliative and Cancer Care Clinical Resource and Audit Group (1994) Palliative Cancer Care Guidelines HMSO Print Centre Edinburgh

Thomas D Flaherty J Morley J (2001) The management of chronic pain in long term care settings Annals of Long Term Care (Supplement 11) 3-20

Torti F Gwyther L Reed S Friedman J Schulman K (2004) A multinational review of recent trends and reports in dementia caregiver burden Alzheimers Disease and Associated Disorders 18 99-109



Tresolini C Pew-Fetzer Task Force (1994) Health Professions, Education and Relationship-Centred Care: A report of the Pew Fetzer Task Force on advancing Psychological Education Pew Health Professions Commission San Francisco California

Tsai P Chang J (2004) Assessment of pain in elders with dementia Medsurg Nursing 13 6 364-369

Twycross R (1980) Hospice care-redressing the balance in medicine Journal of the Royal Society of Medicine 73 475-481

Vallely S Evans S Fear T Means R (2006) Opening the doors to independence: a longitudinal study exploring the contribution of extra care housing to the care and support of older people London: Housing Corporation and housing 21

Volicer L Hurley A (1999) Assessment of behavioural symptom management in demented individuals Alzheimer's Disease and Associated Disorders 13 (Supplement 1) 59-66

Volicer L (2001) Management of severe Alzheimer's disease and end of life issues Clinics in Geriatric Medicine 17 2 377-391

Wadsworth Y (1998) What is participatory action research? Action Research International Paper 2 Available on line: <http://www.scu.edu.au/schools/gem/ar/ari/p-ywadsworth98.html>

Wallis S (1999) Changing practice through action research Nurse Researcher 6 (2) p.5-15

Ward R Vass A Aggarwal N (2005) What is dementia care? 1. Dementia is communication Journal of Dementia Care Nov / Dec 16-19

Waterman H Webb C Williams A (1995) Parallels and contradictions in the theory and practice of action research Journal of Advanced Nursing 22 779-784

Waterman H (1998) Embracing ambiguities and valuing ourselves: Issues of validity in action research Journal of Advanced Nursing 28 p101-105

Watson B Reynolds J Clarke C (2003) An investigation of distress in learning disabilities: the development of an assessment instrument Northgate and Prudhoe NHS Trust

Webb C (1990) Partners in research Nursing Times 86 (32) p40-44

Weiner D Peterson B Ladd K McConnell E Keefe F (1999) Pain in nursing home residents: an exploration of prevalence, staff perspectives and practical aspects of measurement Clinical Journal of Pain 15 2 92-101

Williamson G Prosser S (2002) Action research: politics, ethics and participation Journal of Advanced Nursing 40 (5) p.587-593

Woodrow P (1998) Interventions for confusion and dementia 4: alternative approaches British Journal of Nursing 7 20 1247-1250

World Health Organisation Expert Committee (1990) Cancer Pain Relief and Palliative Care Technical report series No 804 World Health Organisation Geneva

World Health Organisation (2002) World Health Organisation definition of palliative care <http://www5.who.int/cancer>

## List of Appendices

Appendix no.	Title
Appendix 1	Services that participated in needs assessment
Appendix 2	Information letter (needs assessment)
Appendix 3	Needs assessment interview schedule (PWAD)
Appendix 4	Needs assessment interview schedule (Carer)
Appendix 5	Needs assessment interview schedule (Service provider)
Appendix 6	Needs assessment interview prompt cards
Appendix 7	Members of West Lothian Dementia Palliative Care Project Steering Group
Appendix 8	People with a Dementia who participated in needs assessment interviews
Appendix 9	Carers who participated in needs assessment interviews
Appendix 10	Service providers that participated in needs assessment interviews
Appendix 11	Example of data analysis
Appendix 12	Baseline data collection
Appendix 13	Baseline data collection findings: Meadow Day Centre
Appendix 14	Baseline data collection findings: Almond Ward
Appendix 15	Beliefs and values questions: supporting family carers
Appendix 16	Beliefs and values questions: assessment and management of pain / distress
Appendix 17	Beliefs and values groups participants
Appendix 18	Meadow Day Centre beliefs and values (Carer support)
Appendix 19	Almond Ward beliefs and values (assessment and management of pain / distress)
Appendix 20	Guidelines for use of DisDAT
Appendix 21	The Disability Distress Assessment Tool (Regnard et al, 2006)
Appendix 22	The Carer's checklist (The Mental Health Foundation, 1998)
Appendix 23	Smith S (2005) Dementia palliative care needs assessment: a focus on spiritual care <u>Scottish Journal of Healthcare Chaplaincy</u> 8 1 13-19
Appendix 24	Smith S (2007) The challenge of assessing and treating pain in dementia <u>Journal of Dementia Care</u> March/April 22-24
Appendix 25	Smith S (2007) Assessing pain in people with dementia 1: The challenges <u>Nursing Times</u> 103 29 28-29
Appendix 26	Smith S (2007) Assessing pain in people with dementia 2 : The nurse's role <u>Nursing Times</u> 103 30 26-27
Appendix 27	Smith SDM (2009) Palliative care for people who have a dementia IN Stevens E Jackson S Milligan S eds <u>Palliative nursing across the spectrum of care</u> Wiley-Blackwell Chichester Chapter 10 142-155

## **Appendix 1**

Representatives from the following services participated in needs assessment interviews

Adults with Incapacity-Mental Health Officer Team  
Advocacy Services  
Carer Support Organisations  
Charitable Dementia Care Organisations  
Day Care – Specialist Dementia Service  
Day Care – Elderly, Non Specialist Service  
Dementia Services Development Centre, University of Stirling  
Dietetics  
Medical – General Practice  
Medical – Psychiatry  
Medical – Palliative Care  
Nursing – Care Home  
Nursing – Community Hospital  
Nursing – Community Psychiatric Nurses for the Elderly  
Nursing – District Nursing Service  
Nursing – Day Hospital  
Nursing – Hospital Mental Health  
Nursing – Palliative Care Services  
Occupational Therapy  
Pharmacy  
Physiotherapy  
Social work  
Speech and Language Therapy

## Appendix 2

Letter for carer

<i>Date</i>	<i>Number</i>
110604	Version 3

Dear (Mr / Mrs)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Name of the study

**A study of palliative dementia care**

### **What is the purpose of the study?**

- a) To assess the palliative care needs of people with dementia and their carers
- b) To find out what can be done to enhance the palliative care provided by services for people with dementia (for example day care centres and hospital wards)
- c) Within these services enhance the quality of life for people with dementia and carers.

The study will take three years to complete.

### **What does palliative care mean?**

Palliative care is the care given to people who have an illness that is progressive. Palliative care aims to achieve the best possible quality of life for people with dementia, their families/carers by

- a) Controlling pain and other distressing symptoms
- b) Helping people with dementia and their families/carers cope with the emotional upset and practical problems of the situation
- c) Helping deal with the spiritual questions that may arise from their illness
- d) Helping people live as actively as possible despite their illness



**New Opportunities Fund**  
**LOTTERY FUNDED**

**Why have I been chosen?**

You have been chosen because you are a carer of a person with dementia. Other people who will be asked to take part are people with dementia and staff and volunteers who provide dementia services in West Lothian.

**Do I have to take part?**

You do not have to take part in the study. If you do take part you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw at any time without giving a reason.

**What will happen to me if I take part?**

The study has two phases; in the first phase you will take part in an interview with the researcher or a group discussion with other carers and the researcher. The interview will take place at a convenient time and location to you. It will last approximately 30-60 minutes; the length will depend on the amount of information you wish to discuss. The group discussion will last around the same time and be led by the researcher and another helper. At the interview and the focus group you will be asked about the following things;

- ☐ What are the needs of the person you care for?
- ☐ As a carer what are your needs?
- ☐ What services and facilities are there to meet both your needs?
- ☐ Your thoughts regarding your quality of life and that of the person you care for?

During the interview the researcher will take notes and afterwards send you a written report of the discussion. The researcher will ask you whether you agree with the report or if you would like to make any changes.

In the second phase of the study the researcher will be working mainly with dementia services to enhance the care given to people with dementia and carers. If you are involved in one of these services, you may be asked to take part in a second interview or group discussion. This will be about the changes that have taken place in the service, what you think about these changes and whether they have made an impact on your quality of life or that of the person you care for.

**Will taking part in this study cause me any problems?**

Taking part in this study will require some of your time and effort;

- Discussing the study with researcher or another person
- Taking part in an interview or a group discussion
- Commenting on the interview report.

Talking about dementia and how it affects you as a carer may cause you to feel upset. The researcher will be sensitive to this happening and help you.

**What are the benefits of taking part?**

You may have ideas about how to enhance the palliative care provided in a service you or the person you care for use. Your ideas will help us to decide what work to do in the second phase of the study. The information you give will help us better understand the needs of people with dementia and their carers.

**What if something goes wrong?**

Whilst taking part in the study you will be able to talk to the researcher or his manager if you are at all concerned about your involvement. Your concern will be listened to and acted upon, following procedures for managing complaints in the National Health Service.

During your interview, if you talk about any concerns you have regarding the treatment you or the person you care for have experienced, the researcher may need to tell someone about this in order to prevent other people receiving similar poor treatment.

**Will taking part in this study be kept confidential?**

All information collected from you during the course of the study will be kept strictly confidential. Any information that you have provided will have your name and address removed so that you cannot be recognised from it. Your name will not be included in any written reports or publications. With your permission your General Practitioner will receive a letter telling them about the study and that you have taken part.

**What will happen to the results of the study?**

The results of the study will be published in a health care journal and a written report will be sent to the services involved in the study and within the National Health Service. It will also be available to participants. The results will be available by April 2007.

**Who is organising and funding the study?**

The study is being organised by the West Lothian Division of NHS Lothian. The researcher is based at St. Johns Hospital. The study has been funded by the New Opportunity Fund and ethical permission was requested from the 'Scotland A' Medical Research Ethics Committee at NHS Lothian.

Thank you for taking time to read this information.

Yours sincerely

Stephen Smith

**Contacts for further information**

Stephen Smith  
(Study co-ordinator & researcher)  
Block 1 / 2 The residency  
St Johns Hospital at Howden  
Livingston EH54 6PP  
Tel. 01506 419666 Extn 3712  
Email. [stephen.smith@wlt.scot.nhs.uk](mailto:stephen.smith@wlt.scot.nhs.uk)

XXXXXXXXXXXXX  
(Senior Clinical Nurse Specialist)  
Hospital Palliative Care Team  
St. Johns Hospital at Howden  
Livingston EH54 6PP  
Tel. 01506 419666 Extn 3062  
Email. [patricia.black@wlt.scot.nhs.uk](mailto:patricia.black@wlt.scot.nhs.uk)

A copy of this information sheet and a signed copy of the consent form will be given to you if you take part in the study.



### Appendix 3

#### Semi Structured Interview Schedule (Person With a Dementia)

(Version 2)

Introduction and thank participant for taking part in the interview.

Acknowledge carer / healthcare professional if they are assisting with the interview.

Discuss project information and complete ethical approval forms.

Number	Question
1	Are you agreeable for a letter to be sent to your GP telling him/her that you have taken part in this study?
2	Are you taking part in any other research or studies at the moment?
3	Can you tell me about how you found out you had dementia?
4	Now that you have dementia can you tell me how it affects you?
5	What are the worst things for you about having dementia?
6	What help have you had because of your dementia?
7	What did you think about the help you have had?
8	What help do you think you need?
9	On the information letter it described palliative care (show prompt cards). When you look at each card, can you tell me about any other needs you may have?
10	Do your family or friends need any help? If yes, what help do you think they need?

Thank the participant for their time and involvement and allowing me to speak with them.

Discuss the report being sent to them and what help they will need to review the report (if any).

Discuss confidentiality of the information provided.

## Appendix 4

### Semi Structured Interview Schedule (Carer)

(Version 4)

Introduction and thank participant for taking part in the interview.

Discuss project information and complete ethical approval forms.

Number	Question
1	Can you tell me how you found out that (insert name) had dementia?
2	Now that (name) has dementia can you tell me how it affects (him/her)?
3	What are the worst things for (name) about having dementia?
4	What help have they had because of their dementia?
5	What did you think about the help (name) has had?
6	What help do you think (name) needs?
7	On the information letter it described palliative care (show prompt cards). When you look at these cards can you tell me about any other needs (name) may have?
8	What help have you had specifically for you?
9	What help do you think you need?

Thank the participant for their time and involvement and allowing me to speak with them.

Discuss the report being sent to them and what help they will need (if any).

Discuss confidentiality of the information provided.

## Appendix 5

### Semi Structured Interview Schedule (Service Provider)

(Version 4)

Introduction and thank participant for taking part in the interview.

Discuss project information and complete ethical approval forms.

Number	Question
1	Can you describe the service you provide for people with dementia?
2	Can you describe the service you provide for carers of people with dementia?
3	For people with dementia who use your service, what palliative care needs do you think they have? (Show prompt cards).
4	For carers of people with dementia who use your service, what palliative care needs do you think they have?
5	Are there any areas of your service that you think would be useful to focus on as part of this study? If yes can you describe please? (Dependant on the nature of the service)
6	Is there anything that you regard as a priority regarding the palliative care of people with dementia and their carers?

Thank the participant for their time and involvement and allowing me to speak with them.

Discuss the report being sent to them and what happens next.

## Appendix 6

### Palliative Care Prompt Cards

Controlling symptoms		
Pain	Sickness	Feeling restless
Feeling agitated	Constipation	Short of breath
Feeling weak	Confusion	Low mood
Loss of appetite	Incontinent of urine	

Help to cope with emotional upset and practical problems

Help cope with spiritual questions  
Hope Religion  
What gives meaning, value and worth  
Individual

Achieve best possible quality of life

Help to live as actively as possible despite dementia

## **Appendix 7**

### **Membership of the West Lothian Dementia Palliative Care Project Steering Group**

Senior Clinical Nurse Specialist,  
Hospital Palliative Care Team, St Johns Hospital

Associate Director of Health and Social Care,  
Dementia Services Development Centre, University of Stirling

Clinical Nurse Manager,  
NHS Lothian (Chair of the Project Steering Group)

Carer representative

Community Psychiatric Nurse for the Elderly  
West Lothian CHCP

Manager, Mental Health Services  
West Lothian CHCP

General Practitioner,  
Bathgate Health Centre

Consultant Psychiatrist,  
West Lothian CHCP

Co-ordinator Dementia / Palliative Care Project  
West Lothian CHCP

Consultant in Palliative Medicine,  
West Lothian CHCP

## **Appendix 8**

People with a Dementia who participated in needs assessment interviews

11 people with a dementia were approached to participate

8 people with a dementia participated in a needs assessment interview

Of the 8 participants, 6 were male and 2 female

7 interviews were conducted jointly with the participant and their carer

1 participant was interviewed without a carer present

2 out of the 8 participants had early onset dementia

All 8 participants provided feedback to the written report of the interview.

## **Appendix 9**

Carers who participated in needs assessment interviews

28 carers were approached to participate

25 carers participated in a needs assessment interview

Of the 25 participants, 9 were male and 16 female

5 of the participants were carers of people with early onset dementia

1 interviewee was a bereaved carer

10 professionals acted as gatekeepers in recruiting carers

7 of the interviews were conducted jointly with a person with dementia and their carer

All 25 of the participants provided feedback to the written report of the interview

## **Appendix 10**

Service providers who participated in needs assessment interviews

64 service providers were approached to participate

63 service providers participated and were interviewed

Of the 63 participants, there were 35 nurses, 11 allied health professionals, 7 day care providers, 6 doctors and 4 others

Of the 63 participants 51 were female and 12 male

62 of those interviewed provided services in West Lothian

1 participant was associated with dementia care services in Lothian

Interviews commenced in March 2004 and were completed in November 2004

6 focus group discussions were conducted with a range of 2 to 9 participants (total participants = 23)

40 individual interviews conducted

Participants represented a variety of services in West Lothian from social care, the private sector, charitable organisations and health care providers (see appendix 1)

Participants were recruited from different levels of organisations, including those providing direct care to those with management responsibilities

62 service providers gave feedback to their written interview reports.



## Appendix 11

### Example of data analysis process

This appendix illustrates the data identified through analysis which led to the development of the theme, the PWAD had an effective social façade which acted as a further barrier to service providers understanding and responding to the family carer's needs. This theme is presented in Chapter seven, section 7.3.

Evidence that supported this theme was extracted from the following seven episodes of data collection:

- First interview with Dillis (carer) 280906.
- Four periods of participant observation with John (PWAD) 311006, 071106, 161106, 211107
- Reflection and action meeting with staff from Meadow Day Centre 051206.
- Second interview with Dillis (carer) 300107.

#### **Data collection method:**

First Interview with Dillis

#### **Data:**

*At this moment John arrived home from Meadow Day Centre. As he came in I was introduced to him. Dillis informed him we were filling out forms for Meadow Day Centre and just sorting things out for there. When he came in he was very keen to have a cigarette, he said he had been waiting all day to have one and the example of him not being clear of what were cigarettes and lighters was very evident at that point, as Dillis had to instruct him to use his cigarettes and lighter appropriately.*

#### **Analysis:**

Degree of John's disability was evident. He experienced visual agnosias, not recognising previously familiar objects. His wife had to instruct him how to smoke a cigarette safely highlighting an ongoing need for continuous observation to manage fire risks. John's response and gestures indicated a desire to minimise the appearance of any difficulty he was experiencing and appear normal.

#### **Data collection method:**

First participant observation with John at Meadow Day Centre

#### **Data:**

*John did not participate in the quiz, it seemed that this was beyond his abilities, although he looked comfortable sitting in the chair with his legs crossed. He occasionally chatted to the man on his left. The gentleman directing the conversation was clear in his questions but John seemed to mumble, or just respond with a nod or one or two words, which were difficult to make out. The gentleman had difficulty hearing what John was saying .....Throughout the quiz John did not answer any questions but looked settled and comfortable and there was nothing untoward that you would observe from him.*

**Analysis:**

John had a demeanour that gave the appearance to those around that he was fine. He appeared to have strategies that gave the illusion he understood what was going on, nodding, mumbling and responding with one or two words. The gentleman he spoke with seemed to expect John to be able to converse with him normally.

**Data collection method:**

Second participant observation with John at Meadow Day Centre

**Data:**

*Whilst in the sun lounge, I tried to ask him a couple of questions but this clearly baffled him, he seemed to think about the question but did not respond. For example there was a discussion about having porridge at breakfast time and who had porridge, who taught them to make it, things like that. I asked John if he liked porridge and he was very clear he did not. When I asked what he would have for breakfast, he seemed to ponder the question but did not respond, this lack of response occurred twice as I repeated the question.....He strikes me as being very conscious of giving off an appropriate social façade within this strongly social setting.*

**Analysis:**

Development of an increased awareness of his severe level of disability and his active pursuit of appearing normal within a social setting.

**Data collection method:**

Third participant observation with John at Meadow Day Centre

**Data:**

*A general discussion took place about James Bond films and different aspects of films in the past. John was looking at the television and listening to the conversation and joined in with some encouragement. He made some quick witted remarks about James Bond and being the next James Bond. He had a clear sense of humour coming through and very jovial and in many ways quick witted in the comments he can make.....*

*I went with him to make sure he was OK and watch him light his cigarette but he took a plastic comb out of his pocket and his lighter and he began to light the end of the plastic comb, thinking the comb was a cigarette. When I informed him of what he was doing he stopped and looked for his cigarettes and managed to light a cigarette. The other people who were smoking in the shed were quite surprised by what he had done and I think this fits with the social façade he gives that everything is OK and he looks relaxed and comfortable but it very much masks the disability he has.. .....*

*The picture he responded to the most was of his daughter. It was quite a large picture in a frame, black and white and looked as though it was taken in the 1960's, a very attractive lady, he kept looking at it and referring to it. It was interesting that he kept looking at it, and spoke in a surprised way as if he had*

*not seen it only a minute or two earlier. It was obvious that his memory of what he had seen in the last two or three minutes was no longer there.*

*Towards the end of looking at the photos, I asked him about his wife Dillis, how was she doing? He said she seemed fine, I asked how they got on at home and he said 'fine', he looked a bit suspiciously at me as if wondering why I was asking this question. I asked if anyone helped them at home and he said 'no, we help each other.'*

**Analysis:**

Quick-witted humour is a strong indicator to those who witness it that he is fine and in tune with what is going on. The incident with the cigarette surprised his fellow clients. He successfully manages to hide his severe degree of disability to those fellow day centre clients he has been around for a number of months. John appeared not to be comfortable with probing questions about his wife and how they manage at home. He demonstrated a degree of suspicion.

**Data collection method:**

Fourth period of participant observation with John at Meadow Day Centre

**Data:**

This data was collected during a card game, which was played with one other client who also had a dementia, a volunteer and myself. The game involved picking up a card and answering the question written on the card.

*I noticed that when John picked up a card and read out a question he was slightly uncomfortable and that people were looking at him, wondering if he would be able to give an answer. It felt like there was a bit of pressure on him and I was trying not to look at him directly. At one point he said, 'you are staring at me waiting for an answer'. It did feel like he felt under some pressure.....*

*At one point he said. 'oh you are a nosey bugger asking me all these questions'. Although this was said in fun there was an element of annoyance in what he was saying.*

**Analysis:**

In conjunction with his social façade John consistently did not like to be asked questions. He did not like to be the focus of attention. John's wish for privacy, social façade and avoidance of situations where he is in the spotlight would have a direct impact on minimising any account he would give of the care he receives from his wife.

**Data collection method:**

Reflection and action meeting with staff from Meadow Day Centre

**Data:**

*Jean commented after reading the accounts (notes from periods of participant observation with John) that she felt there was a lot to do with social façade coming through in these notes and that he was working hard at trying to appear ordinary and diminish the degree of disability that he has.....*

*\*\*\*\*(social work student) was taken with the amount of effort that is involved in, 'keeping up with appearances', or to 'looking like he is on top of things'. Tam read the accounts and felt that they reflected what he saw and his knowledge of John.....*

*Our discussions led to the fact that it had taken a great deal of time on my part (Stephen) to get to know him (John) and his wife (Dillis) and to understand the situation and how on earth can that happen for care staff or care professionals to know what is happening and then provide appropriate help. It is very difficult for help to be provided because of his social façade and his way of covering up problems but also the very important fact that he does not like people being in the house and does not like help being there and that impacts on his wife also.*

**Analysis:**

Day care staff verified their impressions of John and the notes from participant observation. There was agreement regarding his social façade and behaviour, which aims to minimise the impression of a disability. A concern was expressed that only through this action research process, namely the large amount of data gathered and time spent with John and Dillis, a real picture had emerged of John and the care he requires. How professional carers could come to a similar understanding of the reality of the situation was felt to be concerning. The need for continuous contact with a professional carer who knows them over time was felt to be the most positive strategy.

**Data collection method:**

Second interview with Dillis (John's wife)

**Data:**

*Stephen spoke of the social façade (John) when he is in a social situation in day care and that he really has to work hard to appear in control of things and that for example at the meal table using cutlery and eating his food and also his general behaviour. Stephen sensed that in some ways it was quite a strain for him to look like things were OK. This was also an important issue in regard to finding support for Dillis, that he himself gives very little away, and his problems are not evident and therefore are not so evident with regard to Dillis' needs in the care she provides for John. Dillis and her daughter very much agreed with these comments.....We discussed the annual review that John went to with the General Practitioner, Dillis and her daughter found this not to be a helpful meeting.....He (GP) asked John one or two questions about his date of birth and things and that was all- there was no further direction as to where to go from there.*

**Analysis:**

Dillis, John's main carer confirmed previous analysis that John's social façade hid his disability. A direct example of the consequences of this was provided in the form of their annual review meeting with the GP. The GP focused his questions on John, his degree of disability was missed as John adopted his normal coping strategies and behaviour. The outcome was disappointing for Dillis no future direction or support outcomes were identified. This identified that John had an effective social façade which acted as a further barrier to service providers understanding and responding to the family carer's needs.

## Appendix 12

### Plan for collection of baseline data

Number	Information to be collected	Rationale	Method
1	Physical description of setting and environment. Number of bedrooms, common areas, staff areas, quiet rooms, dining room. Décor, signage, Dementia friendly environment? Access and use of any outdoor areas?	Provide an accurate description of the environment and an understanding of both the positive and challenging aspects	Question staff Participant observation
2	Staffing within the service, numbers of staff and grades. Include all staff caring and support staff associated with the service, e.g OT, Chaplain & volunteers.	Identify baseline staffing and monitor changes over the period of the project. Potential for significant impact on the outcome of the project need to be able to demonstrate accurate portrayal of staff changes.	Review rotas and staffing level agreements. Track changes to staffing over time.
3	Information flow of patient details / history from service to service, on admission and to and from other agencies, at the point of discharge.	Understand information flow and the positive and challenging elements of this.	Participant observation Review documentation Quality questionnaire
4	Communication with other services / agencies caring for people with dementia e.g. GP's, DN's, CPNE's, social work staff, Macmillan nurses, Alzheimer Scotland.	Establish which internal / external agencies the service communicates with and why.	Question staff Participant observation Review documentation
5	How do staff approach and manage assessment, care planning and delivery and ongoing review.	To understand how the assessment, planning, delivery and reviewing of care is undertaken and who participates in this process.	Review documentation Participant observation Quality questionnaire to staff and carers.
6	Identify how family and friends are involved in assessment, planning and care delivery. How do staff	Identify formal and informal systems of family involvement in	Review documentation Participant

	communicate with families / friends.	assessment, planning and care delivery and communication with family.	observation Quality questionnaire to staff and family / friends.
7	Identify person centred approaches to care.	Understand to what extent the provision of care is based on each individual person. Give examples.	Participant observation Review documentation Quality questionnaire to staff and carers.
8	Support and development of staff. Describe how training, education, supervision, review of crisis or critical incidents, appraisal takes place.	Understand systems in place and how training and development is approached.	Question Charge Nurse Review documentation
9	Determine how clients are involved in activities when using the service.	Understand what activities are available for clients, to what degree are they based on their interests and wishes. What facilities are available for activity, physical, environment, staff?	Participant observation Review documentation Quality questionnaire to staff and carers.
10	Have there been any internal or external audits or project work conducted in the last year, eg care commission, mental welfare commission, staff projects.	Identify and understand any project work undertaken. Identify outcomes of internal and external audits and resulting action taken.	Review documentation Question Charge Nurse.
11	Determine the complaints procedure. Identify the nature of any complaints. Any themes, how are they resolved. How easy is it to make suggestions / complain.	Understand the process, how it is used, the nature of complaints and any resulting action.	Review documentation relating to complaints Question Charge Nurse
12	A measure of the quality of care provision.	Use a consistent measure to evaluate	Questionnaire given to staff

	Short questionnaire developed.	two perspectives of the quality of the service (provider & relative / friend). Can enable measurement of changes over time.	and family / friends.
13	Classification of the care profile of each of the five services using the REPDS (Revised Elderly Persons Disability Scale) Permission granted to use tool by R Fleming.	Used as a comparator to describe the participating services. Provides data related to seven domains and will enable an initial profile of each service. Could be repeated if useful.	Complete REPDS evaluation for each client in the five services during a given timescale.

## Appendix 13

### Findings baseline data Meadow Day Centre (MDC)

No	Information to be collected	Findings
1	Physical description of setting and environment. Number of bedrooms, common areas, staff areas, quiet rooms, dining room. Décor, signage, Dementia friendly environment? Access and use of any outdoor areas? Describe both positive and challenging aspects of environment	When and from whom was data collected:
		Data was collected during a period of participant observation over two days (3 & 4 May 2005), and through discussions with staff and clients.
	<p>MDC is situated close to the centre of XXXXXX. It has a multifunctional use but its primary function is to provide a day care service for elderly people around the XXXXXX area. It is set off the road and has parking facilities to the front of the building. There is an enclosed garden, which is accessible via ramps from different rooms in the building. A number of the main communal rooms look onto the garden which is beautifully maintained, and provides a very positive element to the environment and the service provided. There is a potting shed which clients can use and there are small seating areas at different parts of the garden. Whilst I was working at MDC, it was being redecorated therefore I didn't get a true picture of the facility. I have visited frequently since then and have witnessed the usual use of the building. There are no bedrooms as its purpose is a day centre. There is an older original part to the building and a newer extension. There are a number of common areas where people come together, a sitting area overlooking the garden, a smoking room, a room used for those taking part in crafts and a dining room. The garden provides a further communal area so there are a number of options for people should they wish to sit with others or sit peacefully themselves. There is a room the Dementia Care Support Worker uses to work with those clients who have a dementia. The décor is generally bright and cheerful and the space feels open. The dining room has a mural painted on the wall, which contains animals and scenes from nature. This could be 'off putting' for people with a dementia in regard to their perception of the environment clearly seeing and distinguishing walls, floors etc. Disabled toilet facilities are available and the staff use coloured toilet seats to aid those service users with visual impairment. The signage could also be confusing as brightly coloured pictures are used for example as signs for the toilet. More standardised black writing on a yellow background with the use of simple pictures and writing could be helpful. Automatic lights are used in the new part of the building.</p> <p>One of the challenges of the building is to not make it look like a community centre. This can be challenging as a number of different groups, with different purposes use the building, therefore keeping it looking a particular way is problematic.</p>	
2	Staffing within the service,	When and from whom was data collected



	numbers of staff and grades. Include all staff caring and support staff associated with the service, e.g OT, Chaplain & volunteers.	Discussion with staff and looking at MDC documentation.
	<p>MDC has a philosophy where everybody mucks in to do the work. I witnessed this first hand as many of the staff were involved in decorating the building, not only the decorators!</p> <p>Staff in the centre include a manager (full time, 36 ¼ hrs), two full time and one part time care workers, part time admin assistant and cleaner. There are two bus drivers who also work part time. The staff are supported by six part time volunteers who work between 4 hours to 18 hours per week.</p> <p>There are other transient members of staff for example young people who are working through 'New Deal' placements and other people who are completing community service. The amount however of this involvement is variable at any given time.</p>	
3	Information flow of patient details / history from service to service, on admission and to and from other agencies, at the point of discharge. Determine both positive and challenging aspects.	When and from whom was data collected:
		Discussion with staff and clients Review of documentation.
	<p>A referral form is completed , which can be done over the phone and an assessment is completed, usually in the persons home. A range of professionals refer to the service, eg. Occupational Therapists, Community Psychiatric Nurses for the Elderly, Social Workers. Clients can also self refer. It is unusual to get a good referral letter that contains helpful information. During the assessment a dependency score is worked out.</p> <p>When leaving MDC information is not commonly asked for. It is possible that a client may go on to use another service and the centre staff would be unaware of this, family or other professionals would need to keep us informed, this makes passing on information challenging. Potentially useful information, gleaned over a long period of time about a client, could be lost as there is a break in the communication link between services.</p>	
4	Communication with other services / agencies caring for people with dementia e.g. GP's, DN's, CPNE's, social work staff, Macmillan nurses.	When and from whom was data collected:
		Review of documentation including annual report and discussion with staff.

	<p>A number of the professionals mentioned above contact the service to discuss clients, staff also make contact with external professionals if there are concerns or problems. Nurses pop in occasionally to see their clients or have a discussion with staff. MDC staff attend local multiprofessional liaison meetings which include their clients, which are held regularly and a useful way of MDC providing information to others and networking. Service providers that attend include Psychogeriatricians, social workers, CPNE, health visitors and representatives from Crossroads and SHED's.</p> <p>This year MDC have been the springboard for the development of a dementia strategy and clinical pathway within West Lothian. They initially brought together a group of professionals to look at dementia care within MDC but, in accordance with need, this work has taken a broader focus across West Lothian.</p> <p>MDC would not have contact with Macmillan Nurses and generally little contact with General Practitioners.</p>	
5	How do staff approach and manage assessment, care planning and delivery, ongoing review.	<p>When and from whom was data collected:</p> <p>Review of documentation, discussion with staff.</p>
	<p>Following assessment of dependency and likes and dislikes, a client is invited to attend and if appropriate take part for example in the Thursday craft group. The assessment leads on to ways in which MDC can practically help the person. For those clients who have a dementia reviews are held 3 monthly, for other day care attenders reviews are held every 6 months. Everyone at the centre has a say in the review and can contribute their thoughts to the discussion. Changes are recorded on the assessment documentation. Generally people who have a dementia who attend MDC have a higher dependency rating.</p> <p>The assessment provides the individual documentation for that client. There are no specific care plans written for each client as the review adopts a more general approach. Potentially for those clients who attend who have a dementia this may be worth investigating for the future.</p>	
6	Identify how family and friends are involved in assessment, planning and care delivery (formal & informal). How do staff communicate with families / friends.	<p>When and from whom was data collected:</p> <p>Discussion with staff, participant observation and review of documentation.</p>
	<p>As MDC provides respite for carers, it is not the norm for family to attend the day care centre. Occasionally at the beginning a family member may attend but usually that is all. During the initial assessment a family member is present to provide information about the client and give an overall picture of how the client is doing what help they have and any particular problems. Staff and drivers of the buses have ongoing contact with family members during pick up and drop off times. Carers groups have been held infrequently but staff feel they have had a variable response, seven people attended the last meeting. Carers are given Carers of West Lothian information packs by way of providing general information. A newsletter is sent out which provides information about activities and holidays for example. On occasion staff receive phone calls from relatives but generally staff would try to avoid phoning family unless it is a necessity as they wish to protect the families respite time.</p>	
7	Identify person centred	When and from whom was data collected:

	approaches to care.	Discussions with staff, participant observation and review of documentation.
	<p>Clients are given choices during their time at MDC. A variety of activities are offered and options given whether they wish to participate or not. Activities such as quizzes, dominoes, darts, snooker, trips on the bus and craft and exercise sessions are available. Options are also provided in respect of choosing a menu each day.</p> <p>Following initial assessment clients are informed of the activities that are available and a discussion takes place regarding what interests them.</p> <p>During participant observation I observed a positive example of person centred care. A lady came into MDC and appeared a bit agitated and restless, the staff worked out whether there would be a seat available for her on the minibus and offered her a trip on the bus as they went round to collect the clients in the morning. The lady loved going on the bus and was clearly pleased, the staff's knowledge of her likes and dislikes enabled this simple but useful intervention to take place.</p>	
8	Support and development of staff. Describe how training, education, supervision, review of crisis or critical incidents, appraisal takes place.	<p>When and from whom was data collected:</p> <p>Discussions with staff</p>
	<p>Training can be difficult and restricted to odd days due, in principal, to funding. There is a budget of £500.00 per year for training. An application has been sent for funding to enable two care workers to commence SVQ level 2 &amp; 3 training. A training plan is in place for volunteers and has covered such things as first aid, disability awareness, communication and attitudes to older people and food handling regulations. A session on drug and alcohol issues was recently held for staff.</p> <p>In respect of supervision the Manager supervises the staff, and the chair of the management committee supervises the Manager. The manager also liaises with 2 or 3 other members of the management committee. Supervision for the volunteers involves meeting with them and discussing particular issues, a structured process of supervision is not in place. It can be challenging supervising and ensuring appropriate work for those working at MDC undertaking New Deal and Community Service placements. Their brief placement and the little opportunity given before their placement to see where their strengths and interests lie is challenging.</p>	
9	Determine how clients are involved in activities when using the service.	<p>When and from whom was data collected:</p> <p>Participant observation, review of documentation and discussion with staff.</p>
	<p>A planned programme of activities is in place for each day. Clients are given options as to whether they participate or not. The dementia care support worker has a variety of other activities and resources particularly for people who have a dementia; for example quiet music, incense, local papers, flash cards and some games e.g. Hoopla. A natural separation exists between those clients who have a dementia and other people who use a variety of services offered by MDC.</p> <p>There are a range of activities offered which are separate to the day care activities, for example quilt making, geneology, a spiritualist church uses the building on a Sunday morning. Users of these services don't necessarily take part in day care activities or the lunch club, hence there are different groups of people who use the service.</p>	

10	Have their been any internal or external audits or project work conducted in the last year, eg care commission, mental welfare commission, staff projects.	When and from whom was data collected:
		Discussion with staff and review of documentation.
	<p>The Dementia Care Support Worker conducted a project specific to people with dementia. He introduced the provision of cranberry juice and the provision of a quiet space for people to have lunch. This was initiated due to a concern about people with dementia not eating well during lunchtime and the current lunch venue being noisy and distracting.</p> <p>MDC has to provide annual returns to West Lothian Council regarding attendance, referrals, this information along with financial information is provided in an annual report.</p> <p>MDC has participated in West Lothian Councils Best Value report involving questionnaires to users of services.</p> <p>MDC does not have to be registered with the care commission although the commission have visited once and provided some useful points. On an annual basis questionnaires are given out to clients asking their views about the service and requesting any ideas or suggestions they may have to improve the service. In reality the Manager found little useful information came from the questionnaires but it was one way of asking people their views.</p>	
11	Determine the complaints procedure. Identify the nature of any complaints. Any themes, how are they resolved. How easy is it to make suggestions / complain.	When and from whom was data collected:
		Review of documentation and discussion with staff
	<p>Information regarding how to make a complaint is included in the client agreement form and details are also displayed on a notice in MDC.</p> <p>No written complaints have been received but verbal complaints have come in with regard to food' always getting peas with meals, when costs go up and challenges faced by different organisations using the building and meeting their differing needs.</p>	
12	A measure of the quality of care provision. Short questionnaire of seven questions.	When and from whom was data collected:
		A questionnaire was given to 14 staff and volunteers who work within Acredale House. Ten questionnaires were returned, a response rate of 71%. Eighty percent of questionnaires included written comments.
13	Classification of the care profile of	When and from whom was data collected:

	each of the five services using the EPDS (Revised Elderly Persons Disability Scale) Permission granted to use tool by R Fleming.	REPDS completed by the Dementia Care support Worker and S Smith for all clients who attend MDC. This included a wide range of people who use the service in a variety of ways, for example attending lunch clubs or spending the day at the centre. Included in these service users are people with dementia. Forty two clients were assessed over a period of two days in June 2005.
--	---	---

## Appendix 14

### Findings baseline data Almond Ward (AW)

No	Information to be collected	Findings
1	Physical description of setting and environment. Number of bedrooms, common areas, staff areas, quiet rooms, dining room. Décor, signage, Dementia friendly environment? Access and use of any outdoor areas? Describe both positive and challenging aspects of environment.	When and from whom was data collected:
		Periods of participant observation, discussions with staff.
	<p>AW is part of a two unit purpose built facility ran as a Private Funding Initiative (PFI). The wing is locked but is built around an attractive courtyard garden. A main corridor forms a 'track' around the corridor with all rooms leading from this. The décor is bright and to a high standard. There are a lot of windows and natural light floods into the rooms. The furnishings are attractive and the area feels spacious. There are three sitting areas for clients, a dining room, single room accommodation and four bays each with two beds. In total there are 30 beds. The outlook is open and gives views of the countryside, the courtyard garden provides an attractive secure outside environment and there is a further enclosed garden with a summerhouse. Signage is black writing on a yellow background with pictures.</p> <p>A challenging aspect of the environment is its remoteness between XXXXXX and XXXXXXXX which may pose transport problems for some.</p>	
2	Staffing within the service, numbers of staff and grades. Include all staff caring and support staff associated with the service, e.g OT, Chaplain & volunteers.	When and from whom was data collected
		Discussions with staff, review of documentation and off duty.
	<p>There are 20 day duty and 11 night duty staff. On day duty there are 9 trained and 11 auxiliary nurses. On night duty there are 2 trained nurses and 9 auxiliary nurses. In total 17 full time staff and 14 part time staff.</p> <p>AW is part of XXXXXXXXXX a Private Finance Initiative (PFI). Catering, domestic, administration and laundry services are provided by the PFI in support of the clinical staff. All residents are provided with a GP service from the local practice and they visit daily. In some instances clients remain registered with their own GP but whilst in the care of AW are cared for by local GP's. Dr XXXXXXXX is the consultant and visits once a week.</p>	

3	Information flow of patient details / history from service to service, on admission and to and from other agencies, at the point of discharge. Determine both positive and challenging aspects.	When and from whom was data collected:
		Discussions with staff, review of documentation.
	<p>For clients being admitted from hospital there is a hospital transfer letter and the persons psychiatric case notes. Medical case notes can be requested but are not routinely sent. From a care home there is a discharge summary. If they are coming from home a CPN is usually involved and they often visit beforehand and give a handover of information about the client or psychiatric medical staff give details of admission.</p> <p>On discharge from the Ward discharge letters are sent, case notes are only returned to NHS services. There would not normally be direct information from day centres the client attends, the CPNE would provide a summary.</p> <p>For clients with open social work cases they will visit and assess and liaise with staff. Social workers complete a care plan and send this along with a discharge letter to the respective care home. This is particularly in the case of adults with incapacity.</p>	
4	Communication with other services / agencies caring for people with dementia e.g. GP's, DN's, CPNE's, social work staff, Macmillan nurses.	When and from whom was data collected:
		Participant observation, discussion with staff and review of documentation.
	<p>There is active communication with other services if the client is in AW for respite or waiting for care home placement. It appears the involvement with other services diminishes once a client is placed in AW for continuing care. As part of the NHS mental health service in West Lothian, AW has access to advisory services for example regular consultant psychiatric services, palliative care team. Services such as physiotherapy, occupational therapy, psychology are available but not regular or routine. Involvement would require specific management of a problem. For example there is no ongoing occupational therapy involvement in therapeutic activities for clients.</p>	
5	How do staff approach and manage assessment, care planning and delivery, ongoing review.	When and from whom was data collected:
		Discussion with staff, participant observation and review of documentation

	<p>A wide range of assessments are carried out for each client routinely for example pressure area, nutritional, moving and handling, annual REPDS and Crighton, these are conducted monthly. There are annual psychiatric and physical assessments completed. On a client record I observed a lady had planned 6 monthly dental checks and 3 monthly chiropody appointments scheduled. Care plans follow a standard NHS framework. There is a front sheet on each clients notes which specifies the assessments to be completed, the frequency of completion and the last review date. Some flexibility is required in the date of assessment for example in the case of a nutritional assessment which may be worth completing ahead of schedule if there was a concern. There is also a daily progress note written, not specific to any care plan. Each client has a key nurse, this information is clearly identified on the door of their room. Through staff discussion it was highlighted however that this is not an opt out, and staff need to know everyone to a working degree but their own clients in more detail. It is key workers who are responsible for reviewing care and changing care plans.</p>	
6	Identify how family and friends are involved in assessment, planning and care delivery (formal & informal). How do staff communicate with families / friends.	When and from whom was data collected:
		Discussion with staff, observation of care and review of documentation
	<p>Family are encouraged to visit the ward prior to admission, meet the staff and have a discussion about the service. Following admission they have discussions with staff about likes and dislikes, flu vaccination and CPR.</p> <p>There is a carers group which families are invited to attend. A number of carers currently help with the care of their relative e.g. helping at mealtimes and helping clients get to bed. On occasion the staff organise an event for clients to which carers are invited.</p> <p>An information pack is being developed to ensure comprehensive and consistent information is given to relatives.</p>	
7	Identify person centred approaches to care.	When and from whom was data collected:
		Discussion with staff, observation of practice and review of documentation.
	<p>A lot of emphasis is placed on food and the choice of meals. Clients are given a choice and for those whose self-help skills are deteriorating they encourage independence through the provision of finger foods. There are efforts taken to ensure eating is a pleasurable time for clients.</p> <p>Care plans identify individual problems and actions to help with these. Clients wear their own clothes and efforts are taken to ensure appearance is kept tidy and appropriate.</p> <p>Managing aggressive behaviours, staff discuss and approach clients in ways which are known to minimize escalation of these behaviours. This is often information that is known, shared and discussed amongst staff but not necessarily included in documentation. It was discussed that this is an area where staff can 'undersell' their dementia care expertise.</p> <p>Flexibility is offered when people get up in the morning and their bathing preferences. Much assessment of preferences is determined by the clients behaviour, for example if a client appears less agitated or aggressive during bathing in the evening rather than in the morning, an evening bathing routine would be established.</p>	

8	Support and development of staff. Describe how training, education, supervision, review of crisis or critical incidents, appraisal takes place.	When and from whom was data collected:
		Discussion with staff and review of documentation.
	<p>During visits to the Wing it is evident that a number of staff are involved in education courses and that staffing permitted this is encouraged. NHS appraisal process in place. Discussion of critical incidents appears to be informal and can occur during routine handovers and ward meetings.</p> <p>In terms of supervision new staff are supervised for example working in pairs following an experienced member of staff. Structured, formal supervision sessions are not routinely in place and senior staff are conscious of this fact.</p>	
9	Determine how clients are involved in activities when using the service.	When and from whom was data collected:
		Discussion with staff and review of documentation. Working alongside volunteer providing activities.
	<p>A volunteer comes one half day per week and works with a group of clients. The ward has a snoezelen room, which is used for this purpose and has a selection of other resources e.g. board games, music. At various times in the year parties and events are organised for clients and carers. The staff feel frustrated that they are unable to offer more in the way of activities for their clients, particularly as the majority are being cared for on a long-term basis. A recent appointment of an activities nurse working 2.5 days per week is being established and increasing occupational therapy input to the wing is being established.</p>	
10	Have there been any internal or external audits or project work conducted in the last year, eg care commission, mental welfare commission, staff projects.	When and from whom was data collected:
		Discussion with staff and review of documentation.
	<p>The mental welfare commission visit annually and complete a report.</p> <p>A Staff Nurse completed an audit regarding hand washing as part of cleanliness champion training.</p>	
11	Determine the complaints procedure. Identify the nature of any complaints. Any themes, how are they resolved. How easy is it to make suggestions / complain.	When and from whom was data collected:
		Discussion with staff and documentation
	<p>NHS complaints procedure in place. Process of complaining explained in poster at to the ward. No verbal or written complaints in the last year.</p> <p>The carers group at AW is an avenue where families make suggestions and raise concerns. Following discussion with staff they are keen to have informal chats to families as they visit and follow up any hunches about potential concerns relatives may have.</p>	
12	A measure of the quality of care provision.	When and from whom was data collected:



	Short questionnaire of seven questions.	A questionnaire was given to 31 staff who work in AW. Thirteen participants responded, (response rate 42%) and eight questionnaires (62%) included written comments. A summary of the results has been provided.
13	Classification of the care profile of each of the five services using the REPDS (Revised Elderly Persons Disability Scale) Permission granted to use tool by R Fleming.	<p>When and from whom was data collected:</p> <p>REPDS completed by staff from AW. Staff already complete this on an annual basis. In total twenty eight REPDS were completed representing current residents at the time of completion e.g. July 2005. A summary of the raw data and the facility profile has been provided.</p>

## Appendix 15

### Beliefs and Values Questions

Supporting carers (family & friends) of people with a dementia

I believe the purpose of supporting carers is .....

I believe carers of people with dementia need .....

If I was a carer of a person with a dementia I would like .....

I believe the Rosebery Centre needs to support carers by .....

I believe the purpose of respite care should be .....

I believe the information we give to carers should .....

I believe the Rosebery Centre could prepare carers for caring by .....

I believe staff at the Rosebery Centre's relationship with carers should be .....

I believe people work well together when .....

I believe change can happen when .....

I believe change is prevented when .....

Other beliefs and values about supporting carers, I think are important are .....

Questions adapted from:

Dewar B (2005) Moving upstream together (training material)

Askham J (1998) Supporting caregivers of older people: An overview of problems and priorities. Paper presented at the World Congress of Gerontology, Adelaide.

## Appendix 16

### Beliefs and Values Questions

#### Pain assessment and management for people with a dementia

I believe the care given to people who have dementia in ward 3 is about ....

If I was in pain and had difficulty telling people about it, I would like .....

I believe the purpose in assessing pain is ....

I believe, in order to assess pain, staff need to ....

I believe in order to manage pain, staff need to .....

I believe the people involved in assessing and managing pain are .....

I believe the difference between distress and pain is .....

I believe the following things limit the way people with dementia in Ward 3, are able to tell us about their pain.....

I believe the people with dementia in Ward 3 can be in pain when they ...

I believe people work well together when .....

I believe change can happen when .....

I believe change is prevented when .....

Other beliefs and values, about assessing and managing pain, which I think are important are .....

Questions adapted from:

Dewar B (2005) Moving upstream together (training material)

Frampton M (2003) Experience assessment and management of pain in people with dementia Age and Ageing 32 3 248

## **Appendix 17**

Participation in beliefs and values focus groups  
Meadow Day Centre and Almond Ward.

Meadow Day Centre: Supporting family carers

Number of groups = 3

Number of participants = 10 (5 staff & 5 volunteers)

Number of groups cancelled = 0

All groups co-facilitated with key person from Meadow Day Centre

Percentage of staff who participated = 67%

Almond Ward: Assessment and management of distress and pain

Number of groups = 5

Number of participants = 13 (6 trained nurses 7 auxiliary Nurses)

Number of groups cancelled = 1

Three of the five groups were co-facilitated with key person from Ward.

Percentage of staff who participated = 62% of day duty, no night duty staff participated.

## Appendix 18

### Meadow Day Centre's Beliefs and Values (Carer support) Summary of beliefs and values focus group discussions

*I believe Meadow Day Centre needs to support carers by .....*

Providing a stimulating and active day care service for clients

Getting to know them

Listening to them

Acting on their worries

Carer's choice to get support must not assume they want it.

Important to somehow identify the main carer

We should clarify what support we give to carers and let carers know.

Should complete an individual assessment at the start of contact

Working out when to intervene and offer help

Keep going when the support offered is rejected.

Need to respond to ongoing assessment of client and carer

*I believe Meadow Day Centre needs to provide direct help to carers by .....*

Important to somehow identify the main carer

We should clarify what support we give to carers.

Should complete an individual assessment at the start of contact

Providing individual support to carers; listening, updating, assessing problems.

Thinking where is an appropriate place to have contact with carers.

During support, control needs to be with the family.

A key contact person is important.

Considering people's perception of the help that is available e.g. social work services.

Using a counselling model to help carers figure out their goals.

Work with the carers perception of things.

*I believe the information we give to carers should .....*

Be relevant to individual needs.

Carers don't get access to our leaflets unless in the building.

Accessible

Useful

Not patronising

Provide an individual response, sort out what information is relevant for carers.

*I believe Meadow Day Centre could help carers by .....*

We could do something if we saw or knew of a need.

Provide a report of what has happened during the day.

Carers groups

Having staff who know about dementia and dementia care.

On occasion carers attending Acredale with clients.

Adapt what we do e.g. provide activities at home for clients.

Provide reassurance.

Make available a range of different things which could help.

*I believe Meadow Day Centre could prepare carers for caring by .....*

Group discussion with other carers can help.

Help families address issues of respite care.

Help families look at how to share care amongst the family, responsibilities amongst families.

Develop ongoing contact with a member of Acredale staff a key contact.

Provision of helpful information.

Be aware that people may not like the word carer.

Talking with them about individual need.

Not telling but helping.

*I believe staff at Meadow Day Centre's relationship with carers should be .....*

Approachable

Carers should be able to feel comfortable approaching staff and volunteers.

Friendly

Key contact

Informal approach

Should be easy to make contact.

Open, honest, willing to help.

Professional e.g. provide good information

*I believe people work well together when .....*

Trust

Openness

People communicate right

People kept up to date

Allow staff and volunteers to use their own initiative, get involved. This is easier for some more than others.

Need to be approachable

When people are understood.

Have a common goal / same aims.

Talk openly and honestly together

When there is empathy and support for one another.

The working group is a steady one

Varying skills of staff and volunteers are used.

*I believe change can happen when .....*

When there is openness

People are listened to.

When new ideas are discussed.

We have a focus for what we are doing.

If you can see things that you are doing make a difference.

*I believe change is prevented when .....*

Money is required

Fear of change

Keep doing what I do

Change can be difficult

Change can be rewarding

Clients and staff can get stuck in what they do.

Some clients don't like new people or new things.

When people say its not my job.

When external agencies look down on the work you do.

External agencies don't know what we do.  
(250406)

## **Appendix 19**

Almond Ward Beliefs and Values (Assessment and management of pain and distress for PWAD)

Summary of beliefs and values focus group discussions

*I believe the care given to the women in Almond Ward, who have dementia, is about.....*

Providing care, consideration and comfort,  
It is about individual care, not just looking after a group of dementia patients.  
Emotional and spiritual care.  
Holistic care is very important – looking at the whole person.  
It is also important to provide care and support for families.  
To understand families and the family carer's needs.  
Providing something extra, for example – recreation activities and giving treats.  
Becoming a substitute family for the women.  
Being an advocate for them.  
Caring for women with dementia of different ages including young women.  
Families of the younger women find it very hard, supporting them.  
Helping women with the fear of other patients and the things they see.  
Continual assessment and monitoring e.g. levels of aggression.  
To achieve best individual quality of life.  
To look after their pressure areas.  
To maintain their overall health as far as possible and safety.

*If I was in pain and had difficulty telling people, I would like.....*

I would like pain relief and comfort.  
I would like people to realise something was wrong.  
It is important to know people as individuals and particularly to recognise change.  
Trust, is an important issue.  
You need to have time to get to know and understand people.  
For someone to explore the possible sources of pain, even though this is difficult.  
To undertake a process of elimination, eg. getting dentist to check for sore mouth.  
To understand the expressions on my face.  
To see if I looked uncomfortable.  
For staff to discuss and report changes and keep each other informed.  
Changes in staff is not good, limits their ability to pick up changes in the women and there is then more pressure on the permanent staff.  
Need triggers to identify a change.  
Staff need training and can effectively use and complete assessment forms.  
To be approached.

*I believe the purpose in assessing pain is.....*

To get appropriate relief and comfort.  
To reduce pain.  
To reassure yourself that you are doing all you can for the person.  
There is no formal assessment in place at the moment.  
It is about staff regularly discussing things together and informal assessment.

Assessing pain is made more difficult when there is lack of staff continuity eg when bank staff are used.

A pain assessment tool would be like an extra guide.

A tool could be used as a base line and it would help to aid with comparisons of when people change.

Success depends on how you the person, know one another and how you work together.

To ensure that there is an adequate level of pain relief.

To have continuous assessment for pain, involving regular review.

To review medicines, prevent unnecessary medication.

Seeing different doctors each day provides different views and opinions.

Telling someone if you pick up on a problem.

Picking up on the simple things that change, eg. walking differently, a zimmer being the wrong height and causing a sore back.

Dealing with people individually.

*I believe in order to assess pain, staff need to.....*

Relationships, involvement and information from relatives is very important.

Information from transfer letters and phone calls is very useful to work with.

Detailed medical history is a bit "hit or miss" as we do not always get medical notes.

Need to involve doctors and consultant.

Watch out for changes particularly in regard to: appetite, aggression, withdrawing, posture, gait, facial expression, words, noises, crying.

Staff need to have regular opportunity to discuss things together and work as a team.

Accept reports from Auxiliary nurses and check them out.

It can be difficult for new staff to pick up the skills involved in this complex work, they need support.

Staff work really well here it is a good team.

*I believe in order to manage pain, the staff need to.....*

Know who to ask for help and advice.

To know about side effects and the combination of drugs and adjusting drugs.

Important to have regular review

Nurses and Medical Staff reviewing changes together is important.

To know the type of pain and how to manage it.

That the GP gets a look at the person and treatment plans are fed back to staff.

In the case of a fracture, restrict mobility, place on close observation.

Auxiliary nurses can act as a trigger in the chain of events to assess and manage pain.

Take action to prevent pain e.g. keep the women mobile. It is not always about drugs.

First thing is an assessment and find the cause.

Staff continuity is important.

It is the simple things that can cause distress e.g. feeding people in an effective way.

Ensure the relatives are involved, they can provide useful information.

To know about the history, possible causes.

To respond and acknowledge the relatives concerns about pain.

It's about constant checking.

Can be about providing emotional support.

*I believe the people involved in assessing and managing pain are.....*



All the nursing staff – in particular those nurses who provide very “hands-on” care, for example: the auxiliary nurses.

It is important to work with the relatives, show them care.

Important to be careful of family worries about pain, be appropriate.

For the GP to review and to be involved.

The Palliative Care Team can provide useful input although not contacted often.

Palliative Care Team help with drug dosages and conversions.

The Consultant Psychiatrist is important if cases are unclear as to whether pain or distress is due to psychiatric illness, or a physical cause.

Essentially, anyone with meaningful contact – for example, a friend, domestic staff, hairdresser.

Working in pairs is important, particularly for new staff / staff unfamiliar to the ward.

Providing ongoing feedback is important.

Important to have regular staff.

*I believe the difference between distress and pain is.....*

I think distress and pain go hand in hand.

Pain is a form of distress.

Distress can equal agitation.

Emotional distress can also be present.

For the odd few patients it is not clear as to what is distress and what is pain.

In the majority of patients, it is OK to separate distress and pain.

Distress is more a mental/psychological thing.

It can be very difficult to figure out the difference between distress and pain and this can effect treatment.

It is often trial and error that is required.

Distress can be a symptom of pain.

Through knowing the person with dementia and their behaviours, you can tease out what is distress and pain.

Staff need to have a shared understanding of the person, so these issues can be discussed together and assessed.

Staff continuity is important regarding this issue as well.

If someone is agitated it is possible they are more distressed than sore.

You can notice differences in the women e.g. the way they shout or squeal, but difficult to know whether it is distress or pain.

It is unusual for the women to use the word ‘pain’, we have to do the talking for them.

Distress can exist on its own.

Distress can be caused by anxiety, confusion.

Important to consider we are all different, have different pain levels etc.

Useful to err on cautious side rather than ignore potential distress or pain.

Useful to review all medications and check for side effects.

It can be like a guessing game, knowing the difference between pain and distress.

*I believe the following things limit the way the women in Almond Ward are able to tell us about their pain.....*

Particularly confusion.

Where there is poor communication.

Where words are not right – people find it difficult to express the right word.

When the women do not know you and do not understand what you are saying.

When the women do not understand the pain they are experiencing.

When there are memory issues –for example: when women cannot remember the pain they have had, or when it started, the parts of their body.

Their dementia itself.

It is important to report everything and get things checked out, particularly the auxiliary nurses

Some of the words the women use can be indicators of pain

It is very much about getting to know them and understand how they speak, their behaviour and their words.

It is important to have formal chats and time with them.

When the women can't focus or concentrate.

Need to respond to differing agitation, noise level.

*I believe the women in Almond Ward can be in pain when they.....*

When they show guarding of particular areas.

When they wince.

When their facial expressions change but it is important to know the person beforehand.

It is very important to have an individual knowledge of each person.

When some of the women sit awkwardly.

You want to look for actual physical signs of pain, for example bruising, injury or infection.

When their body language changes, or shows evidence of pain.

By the words that are said.

If they have a change in their eating habits.

Useful to have a named nurse involved who can continually assesses over time, for example activity, sleeping, mood and general awareness.

When they suffer from constipation or urinary tract infections.

When they are hungry...some refuse to eat.

*I believe people work well together when.....*

When they are happy.

When they are committed to what they are doing.

When they know each other.

When they want to be here.

It is a difficult place to work and it is important to have a positive attitude.

It is important that people can be themselves and say what they feel.

When people have the same goals and outcomes.

When people feel they are part of a good team, in particular that they communicate well with each other and information is handed over.

People feel secure, trust and respect each other.

The team is inclusive eg involvement of domestic staff.

When there is good banter,

When the care is about the women and one another.

*I believe change can happen when.....*

When people's attitudes are positive and there is receptiveness to trying something different.

It depends on how the change is portrayed.

It also depends on whether people are treated with respect – treated like adults

Whether they are consulted about the change.

Everybody has to want to be involved.

If the change is for the better and is important.

Often people do not initially like change.

When the team is in agreement and there isn't resistance.

Flexibility needed not rigid ways of working.

Change has been useful when you look back and think about poor practices in the past.  
When people like the mental welfare commission highlight an issue and it needs to change.

*I believe change is prevented when.....*

No valid reason for change is given.  
When the change is not feasible or practical.  
When the tools and the skills required for the change to happen are not there.  
When people respond negatively to the change.  
When people do not want it.  
When they do not have the effort required for the change.  
If staff have not been consulted or involved.  
If the change has not been explained.  
When people are frightened of change.  
When people have entrenched ideas.  
Practical things get in the way e.g. staff shortages, resource problems.

*Other beliefs and values about assessing and managing pain, which I think are important are.....*

Looking at alternative therapies  
Looking at each person's religious beliefs.  
What each woman finds individually comforting.  
Being aware of psychosomatic pain, when there is not a particular physical cause but distress.  
Providing things like Reiki, foot massage, physical contact, holding their hand, sitting with them and giving a cuddle can be very positive.  
It is positive to express open emotions between staff and clients.  
That everyone is individual and everyone has different tolerance levels to pain.  
It is important to have knowledge of pain and of the drugs used to ease pain.  
It is important to be able to articulate what is happening particularly regarding different types of pain relief, e.g. the use of acupuncture and massage.  
Showing care and concern.  
For staff to be with the women if they are in pain as it can be frightening.  
To provide a distraction from the pain they are experiencing.  
If training to take place particular need to focus on management of pain and assessment tools.  
Ensuring basic care is the foundation.  
Safety issues are particularly important as we have very vulnerable women here.

## **Appendix 20**

### **West Lothian Dementia Palliative Care Project**

#### **Guidelines for using the DISDAT assessment tool in Rosebery Wing**

- ❑ The patient's key worker (trained nurse) should complete the form but there should be discussion with co-workers or another nurse who knows the patient, it is also good to involve the family in the assessment.
- ❑ Anyone completing the assessment should know the patient.
- ❑ On the first occasion the assessment is being completed for a patient, the form should not be completed all at once but over time.
- ❑ For a new patient to Rosebery Wing the form should not be completed until they have been in the ward for one month.
- ❑ Two people should be involved in the assessment whether a new assessment or a review. The assessment needs staff to discuss the patient, not just state the views of one person.
- ❑ Once the initial assessment is completed a monthly assessment should be conducted thereafter. This should be completed when the other monthly reviews are completed for every patient in Rosebery Wing.
- ❑ The assessment can also be done at any time, if there are changes in behaviour of a patient, either change that occurs when a patient is content or distressed.
- ❑ All new assessments should have a new DISDAT form completed.
- ❑ Following the completion of a new assessment, the front section of the DISDAT should be completed, ie. the section titled context of distress and communication, which helps ease distress. Any information, which describes actions that alleviate distress, should be recorded here.
- ❑ When a new assessment or review is done this should be recorded in the comments sheet. The comments sheet should state whether the assessment is unchanged or if changes have been noted and any actions taken. The comments sheet will remain in the patients care plan as a record of what has been done.
- ❑ Old DISDAT assessments should be filed in the patient's case notes, only the current DISDAT should be present in the care plan.
- ❑ A care plan should be written identifying distress but should refer to the DISDAT tool for further information.
- ❑ To determine the cause of distress go through the clinical decision checklist, remember to discuss this with others.
- ❑ Remember to consider the context of the distress as this can be important.

270606

## Appendix 21

## Appendix 22











